ATTITUDES AND BELIEFS OF DISEASE SEVERITY AND VALUE OF CONTROL IN PEDIATRIC DIABETES

BY
KYNDAL L HETTICH

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE
MASTER OF SCIENCE IN DIETETICS

MOUNT MARY UNIVERSITY
DECEMBER, 2020

APPROVED BY
TARA LAROWE, PHD, RD, CD
DIRECTOR, GRADUATE PROGRAM IN DIETETICS

APPROVED BY
MEGAN D. BAUMLER, PHD, RD, CD
ADJUNCT PROFESSOR, GRADUATE PROGRAM IN DIETETICS

Copyright Statement

ATTITUDES AND BELIEFS OF DISEASE SEVERITY AND VALUE OF CONTROL IN PEDIATRIC DIABETES

KYNDAL L HETTICH

DECEMBER 2020

ABSTRACT OF THESIS

Type 1 and type 2 diabetes in the pediatric population is a challenging disease to manage. Many individuals are involved in the care of these patients including physicians, nurses, dietitians, parents and the patient themselves. Understanding what drives preferred self-management behaviors is critical to preventing long term complications and improve metabolic control. Currently, there is a gap in research to understand patient and parent perceptions of diabetes severity and value of tight control and how it relates to metabolic control, quality of life and depression. This cross-sectional study included 98 patients diabetes patients aged 13-18 years old and one of their parents. Three questionnaires including the Pediatric Quality of Life Inventory-Diabetes module (PedsQL), the Diabetes Attitudes Scale, and the Revised Health Belief Model were implemented to determine the relationship between patient and parent responses and metabolic control. Pearson's correlations found significant relationships amongst variables and ANOVA analysis revealed significant differences between patient and parent responses.

Results of the surveys revealed that patients were able to accurately assess their metabolic control as patients with higher hemoglobin A1c's rated their diabetes as more poorly controlled than patients with lower hemoglobin A1c's (p=0.008). Parent's valued tight blood sugar control more than patients (p=0.000) and also had more concerns related to their child's quality of life in the subcategory of Communication in the PedsQL (p=0.021). Patient's scored their Worry on the PedsQL about diabetes lower than parents indicating more concern regarding blood sugar fluctuations and complications from diabetes (p=0.001). There was a significant but weak positive correlation between length of time since diagnosis and hemoglobin A1c (Pearson's correlation 0.202, p=0.046).

Healthcare providers working with pediatric type 1 and type 2 diabetes patients can feel optimistic in that patients are able to relate their metabolic control accurately. Results from this research can also be utilized to support open communication during clinic visits between patients and parents. Future studies utilizing a longitudinal design with additional follow up will help further support determining how perceptions of illness may play a role in successful self-management strategies and the relationship between quality of life and depression during adolescence.

ACKNOWLEDGEMENTS

Thank you to Dr. Megan Baumler for her unending insight and support for this work and Dr. Marion Toscano for her statistical genius.

TABLE OF CONTENTS

CHAPTER

i. INTRODUCTION

ii. REVIEW OF THE LITERATURE

iii. METHODS

iv. RESULTS

v. DISCUSSION

BIBLIOGRAPHY

LIST OF TABLES

PAGE

TABLE 1: Patient Demographics 40-41

TABLE 2: Correlations Data 41

TABLE 3: T-test comparing patient personal assessment of diabetes control and actual hemoglobin A1c 41

TABLE 4: ANOVA analysis of Pediatric Quality of Life-Diabetes Module patient and parent scores 42-43

TABLE 5: ANOVA analysis of the Diabetes Attitudes Scale patient and parent scores 43-44

CHAPTER I: INTRODUCTION

Diagnosis of type 1 and type 2 diabetes is increasing in the juvenile population (Mayer-Davis et al., 2017). The successful management of diabetes helps to decrease the risk of acute and chronic complications that can occur over time with poorly controlled diabetes (American Diabetes Association, 2002). In the pediatric setting, there are a plethora of health care providers that interact with patients and families to help support and problem solve the ups and downs of a diabetes diagnosis (Mensing, McLaughlin, & Halstenson, 2011). It is critically important for all health care providers and diabetes educators to understand how families view their illness to align with their beliefs and provide meaningful care and help support realistic behavior change.

The Health Belief Model (HBM), is one behavioral approach amongst many that has been used in the self-management of diabetes. The HBM allows one to understand motivations for behaviors and can be a tool used to modify one's practice to meet the patient's and their family's needs. Within the HBM, a patient's decision to perform a health-related behavior is influenced by six factors: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action.

Currently, there is a gap in the research available utilizing the HBM related to patient and parent perceptions of severity of illness and utility of tight control. By instituting research to find relationships between patient and parent perception of diabetes health beliefs related to metabolic control, quality of life, and depression, further clarity will emerge for medical providers, nurses, and dietitians working with this population. This is increasingly important to study as the constant care and management of a chronic illness such as type 1 and type 2 diabetes can lead to increased mental health disorders, lower quality of life and variable perceptions in severity of illness (Harvey, 2015). Research has suggested that children with diabetes may be at risk for higher levels of psychosocial difficulties compared to peers but it is not clear which children are at higher risk (Reynolds & Helgeson, 2011). Current research has found mixed results utilizing the HBM to predict regimen adherence. However, at this time, there are no studies present in the pediatric type 2 population that relate patient and parent perceptions of diabetes to metabolic control or quality of life.

The purpose of this study is to use questionnaires related to the HBM, attitudes about diabetes, quality of life, and depression and determine their relationship with metabolic control. Information from these tools will be related to patient and parent's perceptions of disease.

The significance of this research may provide additional insight into the relationship of perception of illness and value of control for parents and patients and how that belief relates to glycemic control. Analysis of relationships between depression and quality of life scores related to perception of illness severity and value of control may help clarify other factors that play a role in successful or unsuccessful self-management behaviors in patients with diabetes. This study may better clarify how beliefs play a role in care abilities and provide insight to medical providers, nurses, and dietitians to allow them to better support patients with diabetes and their families.

Research Hypotheses

Patients who view the value of control within their diabetes diagnosis as less important will have less metabolic control as evidenced by higher Hemoglobin A1c levels, with better quality of life scores, and less depression than individuals who perceive tight control being more valuable. Parents who perceive value of control as more important will have children with lower Hemoglobin A1c's than parents who control to be less valuable.

Sub-problems

1. Is perceived value of control of diabetes assessed by the Diabetes Attitudes Scale (DAS) able to predict metabolic control?
2. Will patient's self-scoring of their control of diabetes align with the medical definitions of well controlled and poorly controlled diabetes based off hemoglobin A1c value?
3. Will parent's scores on the Pediatric Quality of Life Scale be consistent with how patients score their quality of life?

Limitations

1. Cross sectional study design limiting insight on causal relationships.
2. Utilization of survey data, which is subjective as it is based on self-report.

Delimitations

1. This study will include only English speaking patients and parents.
2. Patients will be between 13 and 18 years old.
3. Patients must be on an insulin regimen with a minimum of one type of insulin analog.

4. This study will only include patients with type 1 and type 2 diabetes. Patients may not have an active medical condition that includes cancer and/or cystic fibrosis.

Assumptions

1. Participants will answer survey questions truthfully.

Definition of Terms

Autoantibodies: an antibody produced by an organism in response to a constituent of its own tissues.

Autoimmune Disease**:** a disease in which the body's immune system attacks its own organs, tissues, and cells.

Basal Insulin Analog**:** long-acting insulin that regulates glucose levels between meals.

Beck's Depression Inventory: A series of questions developed to measure the intensity, severity, and depth of depression in patients with psychiatric diagnoses.

Beta Cell: An insulin producing cell located in the islets of Langerhans.

Bipolar Disorder**:** A brain disorder that is marked by alternating periods of elation and depression.

Carbohydrates: An organic compound consisting of carbon, hydrogen and oxygen that breaks down into sugar and provides the body's cells with energy.

Cardiovascular Disease**:** Conditions involving narrowing of or blocking of blood vessels that may lead to heart attack, chest pain, or stroke.

Continuous Glucose Monitor: Device that provides information on how a person's blood sugars are trending by the insertion of a small sensor that measures interstitial glucose levels every 1 to 5 minutes.

Depression**:** A mood disorder that causes persistent feelings of sadness and loss of interest that can interfere with daily functioning.

Diabetes Ketoacidosis (DKA)**:** complication of diabetes where the body produces high levels of blood acids called ketones due to the liver breaking down fat for energy, which causes the blood to become acidic.

Dyslipidemia**:** Elevated total or low-density lipoprotein cholesterols, or low levels of high-density lipoprotein cholesterol.

Glucose: A type of simple sugar that comes from some carbohydrate containing foods and provides the body with energy.

Gluconeogenesis: Metabolic pathway that results in the production of glucose from non- carbohydrate carbon substrates.

Glucometer: A medical device that measures the amount of sugar in the blood stream.

Hemoglobin A1c: a measurement of your average blood sugar for the past 2 to 3 months.

Honeymoon Phase: When the pancreas is able to continue to produce a small amount of insulin in the body for a short period of time.

Hyperglycemia: An excess of glucose in the blood stream.

Hypertension: High blood pressure.

Hypoglycemia: A low level of glucose in the blood stream, typically a level less than 70 ml/dl.

Insulin: A hormone in the body that moves sugar from the blood stream into the body's cells for energy.

Insulin Resistance: an impaired response to insulin by the body resulting in elevated blood glucose levels.

Metformin: A medication known as a biguanide that works by decreasing hepatic gluconeogenesis.

Morisky Medication Adherence Scale: A validated assessment tool used to measure non-adherence in a patient population.

Nephropathy: A term used to describe disease or damage of the kidney.

Polyuria: production of large volumes of dilute urine.

Polydipsia: excessive drinking as a result of thirst.

Post-Traumatic Stress Disorder: A condition of persistent mental and emotional stress occurring as a result of injury or severe psychological shock.

Prandial Insulin Analog**:** rapid acting insulin taken at mealtime or for correction of high blood sugar levels.

Schizophrenia**:** A medical disorder that affects how a person thinks, feels, and behaves leading to faulty perception, inappropriate actions and feelings, withdrawal from reality and personal relationships into fantasy and delusion.

Screen for Child Anxiety Related Emotional Disorders-41: A child and parent self-report instrument used to screen for anxiety disorders.

Type 1 Diabetes**:** An autoimmune disorder wherein the beta cells of the pancreas are destroyed, leading to the inability of the pancreas to produce insulin.

Type 2 Diabetes: A metabolic disorder characterized by high blood sugar, insulin resistance, and decreased insulin sensitivity. Often related to obesity and limited physical activity.

CHAPTER II: REVIEW OF THE LITERATURE

Introduction

Diabetes diagnoses of type 1 and type 2 in youth have been increasing (Mayer-Davis et al., 2017). The American Diabetes Association (ADA) has published clinical practice recommendations for patients with diabetes to support self-management and decrease the risk of acute and chronic complications. Successful self-management of diabetes cares by patients and families is key in the prevention of complications such as nephropathy, cardiovascular disease, dyslipidemia, and hypertension that can occur over time with poorly controlled diabetes (American Diabetes Association, 2002). As rates of newly diagnosed children and adolescents with diabetes increases, it is important for medical providers and diabetes educators to understand how patients and families view their chronic illness to provide care in a meaningful way. In 2012, incidence rates of type 1 diabetes were 21.7 cases per 100,000 youths each year within the ages of 0-19. For type 2 diabetes, incidence rates were 12.5 cases per 100,000 youth of the same age range (Mayer-Davis et al., 2017). For children 0-19 years old, the average age of onset for type 1 diabetes is highest between 10-14 years old and for type 2 diabetes between 15-19 years old (Mayer-Davis et al., 2017). An additional challenge for children and adolescents diagnosed with diabetes is that the peak of onset is also a time when adolescents are becoming more autonomous and have an increased desire to be like their peers (Bond, Aiken, & Somerville, 1992). Researchers are working to identify more ways to support pediatric patients with diabetes. Some strategies include providing recommendations around the involvement of family functioning and others around the utilization of quality of life assessments in children and adolescents with diabetes (Wit et al., 2008).

To help further develop methods to support patients more effectively, it is important to understand how patients and families interpret their illness, including perceptions around importance of tight control of blood sugars and disease severity and how that relates to disease management. The Health Belief Model (HBM) is one behavioral approach that has been used in the self-management of diabetes (Mensing, McLaughlin, & Halstenson, 2011). It is crucial for diabetes educators to not only be able to provide patients with information and knowledge, but also to consider other skills such as goal setting, problem solving, and helping patients live well with a chronic illness (Mensing et al., 2011). It can be challenging for patients to truly understand the information they are receiving in their clinic visits and if their understanding aligns with the objective data that providers use to define diabetes control, such as hemoglobin A1c. The purpose of this literature review is to critically analyze the evidence on the HBM self-management theory for patients with type 1 and type 2 diabetes. Self-management of diabetes cares is a major contributor to overall health and well-being of the patient. If there are clear connections and correlations that can be obtained through the study of this behavioral approach in improving diabetes cares and outcomes, institutions can implement successful strategies to improve clinical outcomes. In addition, the applicability of commonly used disease characteristic questionnaires in research to determine perceptions of illness severity, attitudes about diabetes cares, quality of life, and glycemic control will be evaluated.

Background

There are significant differences in each type of diabetes. Each has a unique pathophysiology, specific criteria for diagnosis and various ways to achieve successful treatment. The following section will describe the differences between type 1 and type 2 diabetes from the perspective of juvenile diabetes.

Type 1 Diabetes

Type 1 diabetes is a complex autoimmune disorder wherein the beta cells of the pancreas are destroyed, leading to the inability of the pancreas to produce insulin. Without the ability to produce insulin, glucose from carbohydrate containing foods remains in the blood stream and is not transported into the muscle cells, brain, and other tissues that rely on glucose. When glucose remains in the blood stream, blood glucose concentrations may increase to above normal levels, which is known as hyperglycemia. Long-term elevated blood sugar levels can lead to long term serious medical complications.

Etiology and Pathophysiology

As with many autoimmune disorders, the cause the loss of beta cell function in type 1 diabetes continues to be unknown and is likely multifactorial (Zaccardi et al., 2015). One potential factor includes a genetic component (Pociot & Lernmark, 2016). Research has now shown a connection between first-degree relatives of patients with type 1 diabetes in combination with two or more autoantibodies as a predictor of hyperglycemia and diabetes diagnosis (American Diabetes Association, 2018). Examples of antibodies widely used in clinical practice to detect diabetes include insulin, proinsulin, glutamic acid decarboxylase (GAD65), glucose 6-phosphatase, catalytic subunit-related protein (G6PC2 also known as IGRP), islet cell antibody (ICA), and zinc transporter 8 (ZnT8A) (Zaccardi et al., 2015). Further clarification regarding progression is enhanced based off additional factors including age at first detection of antibody, number of antibodies, antibody specificity, and antibody titer (American Diabetes

Association, 2018). Currently, in genetically predisposed individuals, detection of autoantibodies can be made up to years before a clinical diagnosis is made (Zaccardi, et al., 2015). Other risk factors to a diagnosis of type 1 diabetes could be environmental and/or immunity related (Rewers & Ludvigsson, 2016; Szablewski, 2014). Pathophysiology of type 1 diabetes includes selective involvement of beta cells but there does not seem to be inclusion of other Langerhans cell functionality (Zaccardi et al., 2015). As far as researchers know, alterations in secretion of glucagon, somatostatin and pancreatic polypeptide cells are not affected in type 1 diabetes regardless of being part of pancreatic Langerhans (Zaccardi et al., 2015).

Symptoms and Diagnosis

Polyuria is one of the biggest diagnostic criteria for type 1 diabetes (Zaccardi, Webb, Yates, & Davies, 2015). Other signs and symptoms of new onset type 1 diabetes include increased thirst, weight loss, and electrolyte disturbances (American Diabetes Association, 2016). Diagnostic testing can be done multiple ways, including fasting plasma glucose (FPG), or a 2 hour plasma glucose proceeding a 75 gram oral glucose tolerance test (OGTT), or based on hemoglobin A1c criteria (American Diabetes Association, 2018). When comparing these diagnostic methods, the ADA finds both OGTT and A1c to be appropriate methods. To diagnose based on FPG, blood glucose concentration must be greater than or equal to 126 mg/dL after fasting for at least 8 hours (American Diabetes Association, 2018). To diagnose diabetes using an OGTT, a 2 hour plasma glucose would be greater than or equal to 200 mg/dL (American Diabetes Association, 2018). When basing a diabetes diagnosis on hemoglobin A1c, the level would need to be greater than or equal to 6.5%. Finally, a random plasma glucose of greater than or equal to 200 mg/dL in a patient with classic symptoms of hyperglycemia such as polyuria and polydipsia is acceptable criteria to diagnose diabetes (American Diabetes Association, 2018).

Once diagnosed with type 1 diabetes the rate of beta cell destruction varies and there is sometimes a short period where the pancreas is able to produce a small amount of insulin, called the honeymoon phase (American Diabetes Association, 2018). During the honeymoon phase, insulin needs are typically reduced as the pancreas is able to provide some support. The honeymoon phase varies from child to child with some patients never having a honeymoon phase. Typically, the honeymoon phase is shorter in infants and children and longer in adults (American Diabetes Association, 2018).

Treatment

Treatment for type 1 diabetes has improved over the years, with the goal for treatment in pediatric patients being tightly controlled blood glucose concentration and a hemoglobin A1c of <7.5% (Chiang, Kirkman, Laffel, & Peters, 2014). Treatment focuses on both administration of insulin and self-monitoring of blood glucose (SMBG) levels. In regard to exogenous insulin, patients can use a variety of methods to deliver insulin including multiple daily injections with an insulin pen or syringes or continuous subcutaneous insulin infusion (CSII) also known as insulin pump therapy. Patients with type 1 diabetes will often be on different types of insulin to achieve their desired management, which includes both rapid-acting insulin analogs or prandial insulin and long acting or basal insulin analogs (American Diabetes Association, 2018). Rapid acting insulin is administered at meal times and/or if a blood glucose level is high and the patient determines the need to bring their blood glucose level down. Rapid acting insulin must be calculated to match carbohydrate intake current blood sugar, and any involvement of physical activity for accurate dosing (American Diabetes Association, 2018). Basal insulin is used to manage the sugar the body's liver releases and is typically taken once each day when on multiple daily injections. In younger patients this medicine may be given as two separate injections to allow for better blood glucose control.

SMBG is integral to effective management and should be monitored at a minimum before every meal and before bed using a glucometer. To aid in management, patients will often check post prandial blood sugars after a meal, around exercise, and prior to driving to manage hypoglycemia safely (American Diabetes Association, 2018). Patients also have the option to utilize the technology of continuous glucose monitors. Continuous glucose monitors are devices that provide patients with information on how their blood sugars are trending by the insertion of a small sensor that measures interstitial glucose levels every 1 to 5 minutes. Patients can use data from SMBG or continuous glucose monitors to anticipate blood sugar values and act to prevent hypoglycemia or hyperglycemia and as a way to determine if therapy targets are being met (American Diabetes Association, 2018). When used to their full extent, SMBG and continuous glucose monitor data allow patients to problem solve variations in blood sugars over the entire day, and especially around meals, snacks, and physical activity (American Diabetes Association, 2018). Research has shown a relationship between the frequency of SMBG and levels of hemoglobin A1c, with lower hemoglobin A1c levels achieved with increased SMBG (American Diabetes Association, 2018).

Type 2 diabetes

Classification and Pathophysiology

Type 2 diabetes has a significantly different pathophysiology than type 1 diabetes and the understanding of beta cell destruction is less defined than in type 1 diabetes (American Diabetes Association, 2018). There is evidence to support that type 2 diabetes in children is also dissimilar to type 2 diabetes in adults due to more rapid decline in beta cell function and faster development of complications from diabetes (American Diabetes Association, 2018). Type 2 diabetes makes up a much smaller portion of diabetes diagnoses in children but the incidence is increasing. Risk factors for developing type 2 diabetes include a family history of diabetes, older age, obesity (especially around the abdomen), female sex, low socioeconomic status, and race or ethnicity (Mahan & Escott-Stump, 2008; American Diabetes Association, 2018).

Pathophysiology

Typically a child with type 2 diabetes first develops insulin resistance wherein the pancreas continues to produce insulin (American Diabetes Association, 2018). However, the insulin the pancreas is able to produce is not enough, and/or is not recognized by insulin receptors, leading to elevated blood sugars. The defect in insulin secretion is related to a combination of factors including inflammation, metabolic stress, and genetic factors (American Diabetes Association, 2018). Type 2 diabetes in children is caused by a combination of factors including excessive weight, poor dietary habits, and decreased physical activity (American Diabetes Association, 2016).

Diagnosis

There are many diagnostic challenges for type 2 diabetes in children. The current recommendation by the ADA to diagnose type 2 diabetes in children is by hemoglobin A1C results. Some of the challenge in diagnosing type 2 diabetes in children comes from the presence of weight increases in all youth. Historically, patients with type 2 diabetes have been differentiated by their weight. Today, overweight and obesity is common in both type 1 and type 2 diabetes making the distinction between diagnoses is less clear (American Diabetes Association, 2018). The thought used to be that type 2 diabetic patients could not present with diabetes ketoacidosis (DKA) at onset, however, it is now known that DKA occurs in about six percent of patients aged 10-19 years with type 2 diabetes (American Diabetes Association, 2018).

Treatment

First line treatment for type 2 diabetes is lifestyle modification with diet and exercise with emphasis on management of co-morbidities, such as obesity, dyslipidemia, and hypertension (American Diabetes Association, 2018). Changes in diet are made to support eating a balanced diet, moving towards a healthy weight, and making exercising a regular part of life. If changes in diet and exercise are insufficient, medication is appropriate. The only approved oral medication for pediatric patients with type 2 diabetes is Metformin, which is a biguanide and works by decreasing hepatic gluconeogenesis (Chiang et al., 2014). Many pediatric patients with type 2 diabetes will also be on insulin to control blood sugars. The use of insulin is recommended in newly diagnosed patients when it is not clear if it is type 1 or type 2 diabetes, and in patients with a random blood glucose concentration of 250 mg/dL and/or a hemoglobin A1c of greater than or equal to 8.5% (American Diabetes Association, 2018).

Regardless of the type of diabetes a child is diagnosed with, there is a large amount of self-management required to manage diabetes. Improvements in self-management abilities in chronic illness can reduce health care costs (Martire & Helgeson, 2017). Patients and their families learn about the pathophysiology of diabetes, how to count carbohydrates and maintain a healthy diet, along with how to provide medications, and problem solve blood sugars. Management of diabetes is a full-time job and this can place a burden on patients and families. Knowing how and when to distribute responsibilities of care among parents and children can be a challenge. Often having parent involvement in illness management is an advantage for better adherence but as age increases, parent involvement tends to decrease (Martire, & Helgeson, 2017). As patients get older and have a desire to become more autonomous with self-cares, it is increasingly important that they understand the severity of their illness and how to effectively problem solve blood sugars, count carbohydrates and perform necessary diabetes cares.

Quality of Life Indicators and Self-Management Behavioral Approaches

There are many behavioral and lifestyle changes that come with a diagnosis of diabetes, including blood sugar monitoring, insulin dosing, and changes in eating habits. Care regimens are complex not only for the child but for parents as well. Medical providers give targeted recommendations to improve glycemic control and prescribe other tools as able including insulin pumps and continuous glucose monitors. Partnering with medical providers diabetes educators including nurses and dietitians share information and resources and teach skills to help families self-manage their diabetes and minimize serious long-term complications. Precise carbohydrate counting and meal planning as well as daily monitoring of blood sugars are some tools to guide dietary intake. Strategies for self-management take years to learn and technology is becoming a larger part of management. The amount of information one family may need to learn can be overwhelming, not only at the beginning of a diagnosis, but over time as new information is presented. The abundance of knowledge a family must acquire and level of coping with a diabetes diagnosis can have lasting impacts and lead to challenges. Evidence indicates increased mental health disorders, lower quality of life, and variable illness perceptions among youth with diabetes (Harvey, 2015). Having a better understanding of how patients perceive their role in their self-care and their understanding of their disease correlates to the treatment team's definitions can help guide providers in their conversations with patients. For example, if an individual with diabetes has a low quality of life, perhaps interventions around quality of life becomes a targeted intervention to ultimately improve their self-management skills. If an individual with diabetes has little value in having tight control of blood sugars, perhaps more education with the individual on long term risks will be effective in improving self-monitoring behaviors. By finding ways to understand patient attitudes and beliefs better, providers can make targeted efforts and provide pertinent information that the patient may be lacking or misunderstanding.

Assessment of Quality of Life

There are many validated scales to determine quality of life and the interest in assessing levels of quality of life have increased (Polonsky, 2000). Trying to define quality of life specifically is challenging and currently it remains poorly defined (Polonsky, 2000). According to the Centers for Disease Control (CDC), "Quality of life is a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life". Quality of life assessment tools have been developed, including disease specific assessments including diabetes specific. Determining which tool is the best to use in research is dependent on the researchers' goals. This review will provide insight on a few of the quality of life indicators available for use in diabetes specific and/or pediatric populations.

The Diabetes Quality of Life Clinical Trial Questionnaire-Revised (DQLCTQ-R) consists of a fifty-seven item scale that includes eight measurements including, physical function, energy/fatigue, health distress, mental health, satisfaction, treatment satisfaction, treatment flexibility, and frequency of symptoms (Polosky, 2000). Initial studies show that this questionnaire has satisfactory validity and responsiveness to change (Polosky, 2000).

The Diabetes Quality of Life Measure (DQOL) was originally developed for the Diabetes Control and Complications Trial (DCCT) and evaluates the relative burden of a diabetes regimen in type 1 diabetic patients (Polosky, 2000). The questionnaire consists of forty-six core items with an additional ten items for adolescents scored on a five-point Likert scale with 1 meaning no impact, no worries, or always being satisfied and 5 meaning always affected, always worried, or never satisfied. Core items are revolved around treatment satisfaction, treatment impact, worry about long-term complications, and worry about social issues (Polosky, 2000).

Problem Areas In Diabetes (PAID) questionnaire is a twenty-item scale with item representing a different area of diabetes-specific emotional distress. It can be used in both type 1 and type 2 diabetes and each question is answered on a six-point Likert scale with 1 meaning no problem and 6 meaning serious problem. This scale has been found to have high internal reliability, validity has been established, and recent studies have shown it to be responsive to change (Polosky, 2000). There has been the recent development of a second PAID scale, the PAID-2, which is slightly longer with twenty-eight items and additionally differs with food diabetes-specific dimensions including 1) overall emotional distress, 2) interpersonal distress, 3) regimen-related distress, and 4) physician-related distress (Polosky, 2000).

There is also a type 2 diabetes specific scale that can be used to assess quality of life called the Type 2 Diabetes Symptom Checklist. This checklist consists of thirty-four items and it is designed to evaluate the perceived burden of six categories of symptoms related to diabetes 1) hyperglycemic, 2) hypoglycemic, 3) cardiac, 4) neuropathic, 5) psychological, 6) and vision related (Polosky, 2000). Categories are evaluated on a five-point Likert scale with 1 meaning the symptom has not occurred and/or was not perceived as bothersome and 5 indicating the symptom was extremely bothersome (Polosky 2000). This checklist has been found to be valid, reliable and responsive to change (Polosky, 2000).

When looking specifically at pediatric quality of life, there are many questionnaires that can be used including the Pediatric Quality of Life Inventory, the Child Health Questionnaire, the DISABKIDS Chronic Generic Measure, and the KINDLE-R. The Pediatric Quality of Life Inventory (PedsQL) is a brief, standardized assessment measure evaluates children between the ages of 2-18 years old and caregiver perceptions of the child’s health-related quality of life (Nardi, et al., 2008). It can be used in both healthy children and children with acute and/or chronic health conditions (Hullman, Ryan, Ramsey, Chaney, & Mullens, 2011). The measure consists of twenty-three items and is scored on a five-point Likert scale with 0 meaning there is never a problem and 4 meaning there is almost always a problem. The scale has demonstrated good reliability and validity (Hood, Anderson, Butler, and Laffel, 2007). To determine the final score, all results are averaged.

The Child Health Questionnaire (CHQ) measures health-related quality of life in children ages 5-18 years. It can be used with healthy children and those with acute or chronic illness. It consists of eighty-seven items that assess fourteen different psychosocial and physical domains including general health perceptions, physical functioning, bodily pain, role/social emotional functioning, role/social behavioral functioning, parent impact-time, parent impact-emotional, self-esteem, mental health, behavior, family activities, family cohesion, and change in health. Responses are a Likert scale that varies based on the item but each item has 4-6 options for response (Hullman et al., 2011). This scale has demonstrated good internal consistency and good construct validity (Hullman et al., 2011).

DISABKIDS Chronic Generic Measure (DCGM) is used to assess health-related quality of life in children and adolescents between the ages of 8 and 16 years with a diagnosis of a chronic health condition (Hullman et al., 2011). This measure consists of three domains, mental, social, and physical. Within each domain there are two dimensions including independence and emotion, social inclusion and social exclusion, and limitation and treatment. There are two versions of this scale a long and a short. The long version contains thirty-seven items and the short contains twelve items from the long version. Questions are answered on a 1-5 Likert scale with 1 meaning never and 5 meaning always. This scale has been found to be reliable and valid (Hullman et al., 2011).

The KINDL-R questionnaire was developed to assess health-related quality of life in healthy and ill children between the ages of 4 and 16 years. The scale consists of twenty-four items pertaining to six dimensions: physical well-being, emotional well-being, self-esteem, family, friends, and everyday functioning (Hullman et al., 2011). Out of each of the twenty-four items there are sub scales containing four items each and all responses are based off a five-point Likert scale with 1 meaning never and 5 meaning all of the time. Higher scores equals to better health related quality of life and this scale has been determine to have excellent reliability, and good construct and convergent validity (Hullman et al., 2011).

These scales are important to consider when measuring quality of life as there are benefits and limitations to each. Finding a quality of life scale that represents the pediatric type 1 and type 2 diabetes population will be critical for reliable research outcomes. Based off the review of measurements available it seems as if the PedsQL is the most appropriate scale. This scale has advantages as it can be used in both children aged 2-18 and their parents. An additional benefit to this scale is that it can be used in both healthy and acute and chronically ill children. The PedsQL has also shown good reliability and validity in studies. The other scales have more limitations in regard to the age ranges recommended for use and length of the questionnaires. The PedsQL scale is based from twenty-three items and many of the other scales are longer with the DQOL scale being forty-six items and the DQLCTQ-R being fifty-seven items. In addition to measurements of quality of life, self-efficacy of behaviors is an important area to consider in diabetes management.

Self-Efficacy in Diabetes Management

Self-efficacy is a critical concept for diabetes management and it refers to performing diabetes cares such as checking and interpreting blood glucose levels, appropriate use of prescribed medication, regulation of physical activity, and carbohydrate counting and meal planning (Abubakari, Cousins, Thomas, Sharma, & Naderali, 2015). The information gathered from self-monitoring allows patients to inform their decisions for adjustments in diet, exercise, and medications (Abubakari et al., 2015). For endocrinologists and diabetes educators who treat patients with diabetes and their families, it may sometimes feel like they are a broken record with recommendations to increase self-efficacy of cares to improve self-management. There are many counseling approaches that providers may use when working with patients and families on navigating the management of diabetes including, but not limited to, motivational interviewing, social cognitive theory, and the Health Belief Model (HBM). This review describes what the HBM is and the use of the HBM in diabetes research.

The use of the HBM in diabetes research is vast, yet, there are still gaps, especially in the pediatric setting. The following section describes different ways researchers have utilized the HBM to better understand how to support many different types of patients with diabetes.

Health Belief Model

The HBM is a theoretical approach to behavior change used to understand health behavior change and maintenance (Mensing et al., 2011). Within the HBM, a patient's decision to perform a health-related behavior is influenced by six factors: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy, and cues to action. Perceived susceptibility relates to the level of personal vulnerability the patient has about developing an illness. Perceived severity is the perception of the seriousness of the illness. Perceived benefits relate to the perception of whether a behavior will lead to a positive outcome. Perceived barriers are the perception of the costs associated with a behavior. Self-efficacy is the level of confidence a patient has in performing a health behavior. Finally, cues to action is related to external cues that influence action of a health behavior.

The HBM was introduced in the 1950s and since then has been used by researchers to understand motivations for behaviors in many illnesses, including diabetes. Although the HBM had been around for years, most studies in the beginning did not use the model to look at adherence in those who had chronic illnesses (Bond, Aiken, & Somerville, 1992). Rather, they focused on the ability of the model to predict a patient's acceptance or rejection of preventative health recommendations and compliance during acute illness (Bond, Aiken, & Somerville). One of the first studies that looked for relationships between the HBM and a chronic illness such as diabetes was performed by Bond, Aiken, Somerville (1992), in their research titled, "The Health Belief Model and Adolescents With Insulin-Insulin-Dependent Diabetes Mellitus". The goal for these researchers was to test the applicability of the HBM to a young adolescent population with a chronic illness requiring lifelong adherence to their medical regimen. This cross-sectional study included 56 adolescent patients with insulin-dependent diabetes mellitus (IDDM) with ages ranging from 10-19 years. Patients were provided with four questionnaires and one parent was interviewed by telephone to determine the adolescent's compliance. The measurements used in the study included: a) Child-Self-Administered Questionnaire (CSAQ), which was performed by the patient with supervision of an interviewer, b) three Child Compliance Telephone Interviews (CCTIs), which was performed with the patient on three random occasions over a three week timeframe, c) three Parent Compliance Telephone Interviews (PCTIs), which were also performed on the same day that the patient completed their compliance telephone interview, and d) a glycosylated hemoglobin blood test for each patient 4-6 weeks after completing the last compliance interview.

This study found that Benefits-Costs was positively associated with compliance and that threat was not always associated with good compliance but did interfere with Benefits-Costs. If the Benefit-Cost was low, Threat related positively to compliance, but if the Benefit-Cost was high, there was a negative relationship to Threat. Patients were most compliant with cares when there was low perceived Threat and high perceived Benefits-Costs. Researchers also found a relationship between age and compliance; as age increased compliance of cares such as exercise, injections, and testing and eating frequency declined. Based on these results, the authors concluded that using threat as a way to motivate a patient is likely counterproductive and should not be used as a method to increase regimen compliance. This conclusion has been further supported by many additional studies since.

Patino, Sanchez, Eidson, and Delamater (2005) looked at the relationship between health beliefs and regimen adherence in ethnic-minority adolescents with type 1 diabetes. Seventy-four pediatric patients between the ages of 11-16 and their parents completed questionnaires to assess risk perception and regimen adherence. By using three different questionnaires: the Diabetes Health Beliefs Questionnaire (DHBQ), Self-Care Inventory (SCI), and the Diabetes-Related Health Problems (DRHP), researchers discovered that the HBM is not a good predictor of regimen adherence. They found that adolescents perceived that their short-term complication risks were higher than long-term complication risks. They also found that individuals with type 1 diabetes viewed themselves at less risk for short-term and long-term complications than other individuals with diabetes. This study suggests that dietitians and diabetes educators need to be more effective in making the relationship between regimen adherence and complications more understandable to adolescents with type 1 diabetes as a way to improve adherence.

Fortenberry, et al. (2014) took a longer approach of analyzing illness perception among adolescents with type 1 diabetes. Researchers looked at trajectories in illness perceptions of adolescent patients with type 1 diabetes and the association of perceptions with developmental and diabetes-related outcomes. Patients were followed for 2.5 years in 6-month intervals and were between the ages of 10 and 14 years old. At each interval the patients completed measures to determine illness perceptions, diabetes responsibility, and cognitive functioning. These included the Illness Perceptions Questionnaire Revised, the Diabetes Responsibility and Conflict Scale, the Kaufman Brief Intelligence Test, the Pediatric Quality of Life Inventory, and an adapted version of the Self-Care Inventory. Results showed that when adolescents felt like they had more control, they also reported better adherence. As adolescents got older, they viewed their illness as increasing in chronicity and negative consequences, increased personal and treatment control over illness, and had a more coherent understanding of the illness. Understanding how illness perception changes over time may help provider’s better support adolescents with type 1 diabetes.

Fortenberry, et al. (2014) suggests that through disease progression adolescents acquire tools that equip them to determine a hierarchy of self-care behavior. This is equated to adolescent’s developing more intellectually during a period of time that diabetes management responsibility is also beginning to transition. Patient intellectual ability may be a deciding factor in understanding the severity of having diabetes and ability to successfully self-manage diabetes. The results of this suggestion that, to truly understand diabetes, there needs to be an understanding of its severity and the general understanding of one’s illness may help support success in treatment and diabetes control due to the ability to understand the self-management and responsibility that co-occurs with a chronic illness. Although, this may not show in objective measures such as improved metabolic control. These findings are significant due to the dynamic relationship that adolescents with diabetes have with their parents, progression of self-management independence and how these factors may impact diabetes self-management and metabolic control.

Diabetes, the Health Belief Model, and Mental Health

Patients with diabetes are at risk for elevated depressive symptoms and depressive disorders (American Diabetes Association, 2018). Current research reports that one in four patients with type 1 or type 2 diabetes are affected by depression making screening at visits incredibly important (American Diabetes Association, 2018). In regard to other mental health disorders, such as schizophrenia, research also shows increased rates of severe mental illness in patients with type 2 diabetes (American Diabetes Association, 2018). Understanding the mental health of patients is important to provide appropriate recommendations to support the entire health of the patient, not just their diabetes. In addition, if diabetes patients are at higher risk of mental health disorders and providers acknowledge it, more can be done to provide better all-around care or referrals to mental health professionals, if needed.

Gutierrez and Long (2011) researched the HBM in patients with diabetes and mental illness. Scales used to evaluate the relationship between medication adherence and the HBM for patients with diabetes have been successfully developed; it is unclear if these scales also translate to those with diabetes and severe mental illness (SMI). Researchers in Philadelphia sought to assess the validity and reliability of existing HBM scales in this vulnerable population. Through recruitment of 152 patients with diabetes and schizophrenia or bipolar disorder at VA hospitals in the Philadelphia area, it was found that HBM scales were largely reliable in this population, with all but one scale showing strong internal reliability. The scales used included the Morisky Medication Adherence scale and validated scales assessing domains from the Extended Health Belief Model including, perceived benefits, side effects and barriers to diabetes medication taking, perceived susceptibility to and severity of diabetes, diabetes self-efficacy, diabetes loss of control, and perceived diabetes control. Results showed that the HBM scales had good internal reliability in diabetic patients with SMI. These tools may be used reliably in diabetes populations regardless of presence of comorbid mental health diagnoses. Even with strong associations between utilizing the HBM as a method to assess diabetes management adherence, it is important to replicate these findings and relate them to additional measures, such as glucose control.

The HBM can relate reliably to patients with mental illness as adolescents and young adults with type 1 diabetes also can have mental illness, although it may not be schizophrenia and bipolar disorder, specifically. Bernstein, Stockwell, Gallagher, Rosenthal, and Soren (2013) studied the relationship between mental health and juvenile diabetes in their paper, “Mental Health Issues in Adolescents and Young Adults with Type 1 Diabetes: Prevalence and Impact on Glycemic Control.” Within this study, researchers utilized three screening tools to assess the rates and correlation of mental illness to glycemic control of type 1 diabetes youth. A total of 150 patients between 11-25 years old completed three surveys: Beck’s Depression Inventory (BDI), the Screen for Child Anxiety Related Emotional Disorders-41 (SCARED-41), and the Eating

Disorder Screen for Primary Care (ESP). Participants were also asked specifically about insulin omission behaviors. The authors' focus was on specific mental health concerns of depression, anxiety, disordered eating, and insulin mismanagement.

Results of the surveys showed that 34.7% of patients screened positive for one of the measured mental health concerns and 14.7% screened positive on at least two of the questionnaires. Specifically, 11% screened positive for depression and 21% positive for anxiety disorder. Those who had one positive mental health screen had two times the odds for poor diabetes control than those who did not have a positive screen. The authors concluded that adolescents with type 1 diabetes are at risk of mental health disorders and that mental health disorders affect disease management. It is the recommendation of the authors to screen this group more frequently to help identify potential co-morbidities and offer greater mental health support.

The studies by Gutierrez and Long (2011) and Bernstein, Stockwell, Gallagher, Rosenthal, and Soren (2013) show that various HBM scales can be used reliably in diabetes in different age groups and in subjects with or without mental health co-morbidities.

Type 2 Diabetes and the Health Belief Model

Regarding type 2 diabetes, Karimy, Araban, Zareban, Taher, and Abedi (2016) researched adherence to self-care behavior based on the HBM. This cross-sectional study had 210 female patients aged 30-60 years old with type 2 diabetes from Zahedan, Iran. Researchers looked at three measures including demographic and medical information, HBM constructs, and self-care behaviors. Within the HBM, researchers selected thirty-three items related to perceived susceptibility to diabetes complications, perceived severity of diabetes and its complications, perceived benefits of self-care, perceived barriers to self-care, and self-efficacy to self-care. Each item was scored on a five-point Likert scale. For the self-care behaviors, they used a revised Summary of Diabetes Self-Care Activities. Results of the study showed that self-efficacy was the strongest determinant of self-care. Other factors that influenced self-care behaviors were perceived susceptibility, perceived severity, perceived benefits, and self-efficacy. Meaning patients with more perceived severity of disease had better adherence to self-care behaviors. The HBM was successful in its ability to understand self-care behaviors in women with type 2 diabetes. While this study shows adherence in women, it is also important to look at adherence in men as well.

In a study from Vazini and Barati (2014), additional information is gathered about men and women with type 2 diabetes and self-care behaviors utilizing the HBM. This cross-sectional study performed in 2012 included 390 randomly selected men and women referred to Hamadan Diabetes Research Center. Participants were provided with self-administered questionnaires including three sections: 1) demographic variables which included age, gender, education, marital status and family history, 2) self-care behaviors which evaluated self-care behaviors in the past week utilizing the answers yes- always, yes-sometimes, and no, and 3) HBM Theoretical constructs, perceived susceptibility, perceived severity, perceived benefit, perceived barriers, perceived self-efficacy, and cues to action.

Results demonstrated that patients had moderate levels of self-care behaviors and the HBM was able to explain 29.6% of the variance in frequency of self-care behaviors. When separating by age, younger patients had more perceived threats and benefits but less perceived barriers and ultimately higher self-efficacy. The authors equate this result to higher education levels and greater awareness of diabetes complications leading to more ability and better attitudes to perform self-cares. When looking specifically at HBM constructs, perceived self-efficacy, perceived severity, perceived barrier, and perceived susceptibility were the best predictors of self-care. Utilizing these constructions as strategies to promote self-care behaviors may be the most advantageous to achieve optimal self-management. The results of this study are opposite of what was found in the Bond, Aiken, & Somerville study in type 1 patients completed in 1992. This result could be the difference between perceptions of illness between type 1 and type 2 populations.

Discussion

The findings of each of these research articles are significant. The HBM has been shown to relate reliable to patients with mental illness, adolescents and adult women with type 2 diabetes. However, there are no studies to date that include adolescents with type 2 diabetes and the HBM. It is important to know that research has shown reliability with the HBM and regimen adherence due to the relationship between mental health and diagnosis of a chronic illness like diabetes. Quality of life, achieving optimal metabolic control, and becoming an adult all at the same time can be challenging for young patients with diabetes as evidenced by the article, "Mental Health Issues in Adolescents and Young Adults With Type 1 Diabetes: Prevalence and Impact on Glycemic Control". As this study showed, adolescents that scored more positively on mental health screens meaning they had higher risk of mental health concerns and had decreased control of diabetes as evidenced by increased hemoglobin A1c values. However, it should be kept in mind that all of these screens are not diabetes-specific as currently there are no validated screening tools for diabetes and mental health disorders. While the questionnaires used in this study were not diabetes specific, it is helpful to know that even when screens are not disease specific there is evidence of reliability as the article, "Reliability and Validity of Diabetes Specific Health Beliefs Model Scales in Patients with Diabetes and Serious Mental Illness" found. This study surveyed patients with schizophrenia and bipolar disorder. However, even though they did not study depression and anxiety, they found that utilizing screens assessing specific domains of the HBM had reliability in patients with diabetes and severe mental illness. Unfortunately, this study was done in a narrow population of mostly male veterans in the Philadelphia area, making it difficult to know if the results also translate to youth patients or even other adult patients. Additionally, because this study only looked at two specific mental illnesses it is unknown if the patients also had diagnoses of other mental illness such as depression, anxiety, or post-traumatic stress disorder as well. The level of mental illness may influence how participants answered questions. Interestingly, researchers found that perceived susceptibility and perceived severity were not significantly associated with self-reported adherence in this study. This result may reflect the amount of self-care this population performs on a daily basis. It may also relate to a belief that other behaviors related to diabetes care are more influential than medication adherence alone, such as exercise or diet behaviors. Just as with the study with veterans, "Health Beliefs and Regimen Adherence in Minority Adolescents with Type 1 Diabetes", "The Health Belief Model and Adolescents with Insulin-Dependent Diabetes Mellitus" and "Determinants of Adherence to Self-Care Behavior Among Women with Type 2 Diabetes: An Explanation Based on the Health Belief Model" have a limited scope in the population studied. It is difficult to know if a diverse sample of study patients would have similar outcomes with the interventions presented. In addition, each of these studies are cross sectional designs, which makes it difficult to determine directionality of relationships.

Few of these studies consider the role of the family and other networks of social support that may interact with health beliefs and perception of illness. Notably, “The Health Belief Model and Self-Care Behaviors among Type 2 Diabetic Patients” does allude to the role of family and the networks of social support. The authors in this study collected demographic data on marital status and family history of diabetes. They found that if a patient had a family history of diabetes, they exhibited increased levels of self-efficacy and cause to action (Vazini, & Barati, 2014). This could be due to a patient having additional support from their family in performing cares or the patient observing complications that have occurred in other family members leading to cause of action to prevent it from happening to themselves (Vazini, & Barati, 2014).

One large limitation to the conclusions of this particular study include that many of the participants designated themselves as being illiterate (~40%) and the questionnaires were all completed through self-report. Education level and literacy could have played a significant role in how participants interpreted questions and provided their answers. Unfortunately, research in the type 2 population and the HBM is limited in pediatrics. The Vazini and Barati (2014) study does show benefits in self-care behaviors in younger individuals, however, in this study, the younger individuals were between the ages of 30-40 years old, which does not necessarily translate to children and adolescents. Despite these limitations, the Vazini and Barati (2014) study still contributes to the literature and provides additional insight in the relationship of the HBM and self-care behaviors in the type 2 population.

Conclusion

Diabetes is a challenging diagnosis that can affect children at a young age and carries on through adulthood. Adolescents are going through many changes as it is, and at a time they want become more autonomous they have the added battle of performing their diabetes cares. Understanding how both parents and children with a diagnosis of diabetes understand their illness, including their perceived severity of illness and value of control, is important for physicians, dietitians, and diabetes educators to understand and successfully provide care. Many assessment tools are available to determine quality of life scores in diabetes. As this literature review supports, many studies default to using the PedsQL questionnaire although many others are available and show reliability and validity.

When looking towards connecting the HBM and perceptions of illness severity, to date, there have been few studies that have related the HBM and perception of illness severity in children and adolescents. There are even fewer studies that address the relationship with diabetes regimen adherence and ultimately glucose control, especially in the pediatric type 2 population. In addition, there has not been a study that has incorporated the HBM in relation to perception of illness severity of diabetes of both parents and children. Current literature supports that mental illness impacts glucose control. Furthermore, much research supports the use of the HBM as a way to understand the self-management of patients as described by Patino et al. (2005) and Karimy et al. (2015).

As adolescents take over more control of their diabetes cares it is important to fully understand their comprehension of their illness and to detect co-morbid diagnosis of mental health such as anxiety and depression and let this information guide their treatment to ultimately improve disease management. The literature clearly indicates that self-monitoring skills are related to perception of disease and quality of life; thus perception of disease and quality of life could lead to a targeted intervention to ultimately improve disease management. Assessing patient and parent comprehension of illness and presence of comorbidities could easily be incorporated into routine care. One possibility could be through questionnaires such as depression screen, anxiety screen, or a quality of life questionnaire. Another option could be through the type of questioning a provider uses with their patient, really listening to the answers they are providing, and using follow up questions to clarify, if needed. Parents are also insightful and can be an invaluable resource to help understand patients' behaviors at home. Ultimately, the intellectual capacity of the adolescent may determine their proficiency in their disease self-management. While there are no diabetes specific screens for mental health, Gutierrez et al. (2011) showed positive reliability in adult veterans. It is important that future studies consider the role of mental health, parents, and patients' perception of their diabetes to provide appropriate interventions within this increasing and changing population. Further research will continue the initiatives that have already been started in this population to support improved glycemic control. Through additional research we can learn how to utilize tools at our disposal to provide the best care possible for children living with diabetes and support their mental and physical health. The acknowledgement of patient and parent perception of their disease is underutilized as a tool in diabetes self-management.

CHAPTER III: Methods

Current research on pediatric diabetes patients and parental perceptions of illness severity and value of tight control related to metabolic control are still lacking. The purpose of this study is to investigate the relationship between the HBM, quality of life, and depression and the relationship with metabolic control in adolescents with type 1 and type 2 diabetes.

Study Design and Objectives

The study was reviewed and approved by Children's Wisconsin IRB and Mount Mary University's IRB. It was a cross sectional study to determine perceptions of disease severity and value of tight metabolic control of youth with diabetes and their parents and see how perceptions relate to metabolic control, depression, and quality of life questionnaire scores. Information from these tools were analyzed to identify relationships between diabetes perceptions and metabolic control. Secondary aims were to clarify how patient and parent beliefs of illness severity and value of control of diabetes play a role in the ability to perform cares successfully. This study aims to give insight to diabetes educators and medical providers to better support families with diabetes.

Recruitment and Sample Size

Subjects were recruited from an outpatient clinic at Children's Wisconsin in Milwaukee, Wisconsin. The patient population of this clinic is approximately 2000 children with type 1 and type 2 diabetes. The study population included pediatric patients aged 13-18 years with a diagnosis of type 1 or type 2 diabetes and one of their parents. Inclusion criteria were patients diagnosed with type 1 or type 2 diabetes for 6 months or longer, between the ages of 13-18 years old and on an insulin analog. Exclusion criteria included patients or parents who are non-

English speaking, patients only on oral medications for management, diagnosis of cystic fibrosis related diabetes or active cancer diagnosis. Any patient that met inclusion criteria was approached in a regularly scheduled clinic visit to participate in the study. Informed consent was obtained at the time of the clinic appointment. The goal sample size was 300 subjects, which included one patient and one of their parents using the Raosoft online sample size calculator. This sample size was based off a 5% margin of error and 95% confidence interval and population of 2000 patients.

Study Protocol

Three questionnaires were utilized in this study. Patients completed all three questionnaires, which included the Pediatric Quality of Life Inventory-Diabetes Module, The Diabetes Attitudes Scale (DAS-3), and the Revised Heath Belief Questionnaire. Parents completed two questionnaires, the Pediatric Quality of Life Inventory-Diabetes Module for parents and the Diabetes Attitudes Scale.

The Pediatric Quality of Life Inventory (PedsQL) is a standardized assessment measure that evaluates children between the ages of 2-18 years old and their caregiver perceptions of the child’s health-related quality of life (Nardi, et al., 2008). It can be used in both healthy children and children with acute and/or chronic health conditions (Hullman, Ryan, Ramsey, Chaney, & Mullens, 2011). This study utilizes the diabetes specific measure, which consists of 5 subscales for a total of thirty-three questions. Each question is scored on a five-point Likert scale with 0 meaning there is never a problem and 4 meaning there is almost always a problem. The scale has demonstrated good reliability and validity (Hood, Anderson, Butler, & Laffel, 2007). Scoring includes averaging each subscale and recording individual subscale scores in addition to averaging all subscale questions to determine the final score.

The Diabetes Attitudes Scale is a tool designed to assess attitudes about diabetes, specifically attitudes toward health professionals, having diabetes, and attitudes around self-cares for diabetes. This survey was developed by the Montana-Wyoming Tribal Leaders Council (TLC), the Billings Area Indian Health Service (IHS), and Black Hills State University. There are 5 subscales to the Diabetes Attitudes Scale: Need for Special Training (5 questions), Seriousness of Non-Insulin Dependent Diabetes Mellitus (NIDDM) (7 questions), Value of Tight Control (7 questions), Psychosocial Impact of Diabetes Mellitus (6 questions), Patient Autonomy (8 questions), scored on a five-point Likert scale. The need for special training in education subscale assesses attitudes regarding the need for health professionals who care for diabetes to have special training in diabetes for teaching, counseling and behavior change strategies (Anderson, Funnell, Fitzgerald, & Gruppen, 1998). Seriousness of type 2 diabetes subscale assesses attitudes regarding the seriousness of type 2 diabetes (Anderson, Funnell, Fitzgerald, & Gruppen, 1998). The overall value of tight glucose control in diabetes care subscale assesses attitudes about whether the potential benefit of tight blood sugar control is justified when thinking of the cost of to the patient, psychosocial impact of diabetes on patients subscale assesses attitudes toward the psychosocial impact of diabetes on those living with diabetes, and attitude toward patient autonomy subscale assesses attitudes about whether patients should be the primary decision maker in regards to the daily self-care of diabetes (Anderson, Funnell, Fitzgerald, & Gruppen, 1998). Higher scores indicate more agreement.

The third questionnaire, which was only completed by the patient, is a revised version of the Health Belief Questionnaire adapted from the "Diabetes Related Health Beliefs," Brown et al, for the diabetes self-management project at Gateway Community Health Center in partnership with the Robert Wood Johnson Foundation. This questionnaire was scored on a five-point Likert scale with 1 meaning strongly disagree and 5 strongly agree.

Additional results from the PHQ-9 depression screen results and hemoglobin A1c lab results were obtained, which are part of the clinic's standard of care. A depression screen score of more than 9 or a positive response to a question that is included as an automatic positive screen was considered positive. Hemoglobin A1c goals for patients 13 and older are less than 7.5% and considered good control of blood sugars.

Data collection

Patients are scheduled to come to the diabetes clinic every three months. Dietitians in the Children's Wisconsin Diabetes Clinic see each individual patient in clinic every 6 months. Participants were approached by the registered dietitian on their scheduled appointment with their medical provider regardless if the dietitian was scheduled to see them. Once consented, questionnaires were distributed by the dietitian and collected either by the dietitian or given to the front desk upon clinic discharge and given to the dietitian. Demographic, hemoglobin A1c, and depression screens were obtained from the electronic medical record and there were no patient identifiers on the questionnaires. Study enrollment and data collection was conducted for 7 months. Initially, study enrollment was going to continue until the goal sample size was achieved, however due to COVID-19 restrictions, study enrollment and data collection ended early.

Data analysis/Statistical Tests

Data were analyzed using SPSS. Completion and scoring of the Revised Health Belief questionnaire was incomplete, thus only one question was utilized from this questionnaire: “My diabetes is well controlled”. Pearson’s correlations compared results of the revised Health Belief Questionnaire and Diabetes Attitudes Scale to metabolic control, quality of life scores, and depression screen scores. ANOVA analysis was used to determine differences between patient and parent scores on the Pediatric Quality of Life Inventory-Diabetes Module. ANOVA analysis was also completed to determine differences between patient and parent responses to the Diabetes Attitudes Questionnaire. Significance was established at $p \le 0.05$.

CHAPTER IV: RESULTS

The relationship between patient and parent attitudes towards the patients' type 1 diabetes and diabetes control was investigated through questionnaire research.

Demographics

A total of 98 patients (59 male and 39 female) subjects and 94 parent subjects were included in the study (Table 1). Of the 98 patient subjects, 94 had a diagnosis of type 1 diabetes and 4 had a diagnosis of type 2 diabetes. The average age of patient subjects was 15.8 years (+/-1.64; range 13-18 years). The majority of the patients had negative depressions screens (total of 83 subjects) and 14 patients that had positive depressions screens. There was 1 patient with missing depression screen information. The average length of diagnosis was 6.87 years (+/-3.89; range 0.6-16.2years). The average hemoglobin A1c was 8.9% (+/-2.23; range 5.4%-14%) (Table 1).

Pearson's Correlations

Pearson's correlations showed no relationship between hemoglobin A1c and sex, age, diagnosis or depression screen. There was a weak but significant positive correlation between length of time a patient has been diagnosed and their hemoglobin A1c level. The longer the patient was diagnosed, the higher the hemoglobin A1c (Pearson's correlation 0.202, p = 0.046). Length of time since diagnosis also had weak but significant positive correlation with patient scores on the DAS for the subscales psychosocial impact of diabetes on patients and attitudes toward patient autonomy. (Pearson's correlation 0.216, p = 0.032 and Pearson's correlation 0.276, p = 0.006). Higher scores on the DAS indicate agreement with subscale items. This suggests that the longer one is diagnosed with diabetes the more they feel they psychosocial impact of diabetes and the more they value having autonomy in being the primary decision maker for their self-care. There were weak but significant negative correlations between hemoglobin A1c and patient total score for the Pediatric Quality of Life questionnaire, and with patient scores for overall value of tight glucose control in diabetes care on the Diabetes Attitudes questionnaire. (Pearson's correlation -0.214, p = 0.034; Pearson's correlation -0.445, p = 0.00) (Table 2). This suggests that patients with higher hemoglobin A1c's perceive poorer quality of life and see less benefit to tight control of blood sugars. Strong, significant correlations between patient hemoglobin A1c and perceptions of their diabetes control based on the question, "My diabetes is well controlled" on the Revised Health Belief Model scale showed that patients were able to accurately assess their control. Patients with a lower hemoglobin A1c accurately scored their diabetes as better controlled and those with higher hemoglobin A1c rated their control lower indicating less well controlled (Pearson's correlation -0.772; p = 0.000). This remained significant when using a t-test comparing patients with hemoglobin A1c levels of 7.5% or less, which is the American Diabetes Association's target hemoglobin A1 level for most children and those with Hemoglobin A1c levels of greater than 7.5% (p = 0.008) (Table 3).

Table 1: Patient Demographics

	Mean +/- SD	Range
Length of Diagnosis (years)	6.87 +/- 3.89 years	0.6-16.2 years
Hemoglobin A1c (%)	8.9+/-2.23%	5.4-14%

Age (years)	15.8+/-1.64 years	13-18 years
Type 1 Diabetes (n, %)	94 (96 %)	-
Type 2 Diabetes (n, %)	4 (4 %)	-
Positive Depression Screen Score (n, %)	14 (14 %)	-
Negative Depression Screen Score (n, %)	83 (86%)	-

Table 2: Correlations Data

	1	2	3	4	5	6
Patient Depression Screen Score	1					
Total Patient Pediatric QOL	-0.19	1				
Length of time since diagnosis	-0.082	-0.099	1			
Hemoglobin A1c	0.049	-0.214*	0.202*	1		
Patient value of tight control	0.065	0.16	0.002	-0.445**	1	
Parent value of tight control	-0.035	-0.119	0.076	-0.097	0.143	1

*correlation is significant at p=0.05
**correlation is significant at p=0.01

Table 3: T-test comparing patient personal assessment of diabetes control and actual hemoglobin A1c

	Ha1c group	N	Mean	Standard Deviation	Significance
Diabetes Health Beliefs Patient report of control compared to Ha1c	≤7.5%	26	4.54	0.58	0.008*
	>7.5%	70	3.52	0.99	

Surveys

ANOVA analysis was performed to compare patient and parent perceptions of diabetes as measured by the PedsQL and the Diabetes Attitudes Scale. Patient and parent's scores for the subscales of Worry and Communication on the PedsQL were significantly different. Patient's scores for the subscale Worry showed that patients had more problems with worrying that their blood sugars would go high or low, and long term complications from diabetes compared to their parents (57.56 +/-22.08, vs 67.48 +/-19.24, F = 10.99, p = 0.001) (Table 4). There are three questions in this subscale including, "I worry about going "low"", "I worry about going "high"", and "I worry about long-term complications from diabetes". This was the lowest patient score on the PedsQL scale overall. The Pediatric Quality of Life subscale Communication showed that patients feel it is easier for them to communicate to others about their diabetes than what their parents perceive (81.51 +/- 24.2 vs 73.77 +/- 23, F = 5.41, p = 0.021) (Table 4). In the PedsQL, higher scores indicate less impact or fewer problems.

Table 4: ANOVA analysis of Pediatric Quality of Life-Diabetes Module patient and parent scores

Subscale	N	Mean	Standard Deviation	F	P
Pediatric Quality of Life Total Score	Patient: 98	71.82	13.7	0.148	0.701
	Parent: 94	71.08	13.06		
About my diabetes	Patient: 98	64.35	15.97	0.41	0.523
	Parent: 94	65.76	14.45		
Treatment I	Patient: 98	79.64	18.58	1.585	0.21
	Parent: 94	76.27	18.42		
Treatment II	Patient: 98	83.9	16.99	0.372	0.543
	Parent: 94	82.44	16.12		
Worry	Patient: 98	57.56	22.08	10.99	0.001*
	Parent: 94	67.48	19.24		
Communication	Patient: 98	81.51	24.2	5.41	0.021*
	Parent: 94	73.77	23		

ANOVA analysis comparing patient and parent scores on the Diabetes Attitudes Scale showed significantly different scores for each of the following subscales, need for special training in education, seriousness of non-insulin dependent diabetes mellitus (NIDDM), overall value of tight glucose control and psychosocial impact of diabetes mellitus (4.15 +/-0.558 vs 4.4

+/- 0.43 p= 0.001, 3.54 +/- 0.495 vs 4.08 +/- 0.497, p = 0.000, 3.696 +/- 0.458 vs 4.12 +/- 0.411, p = 0.000, 3.99 +/- 0.66 vs 44 +/- 0.46, p = 0.000) (Table 5). In each of these subscales, parents scored the questions higher than patients. This suggests that parent's show greater agreement that health care providers should have special training for teaching, counseling and behavior change techniques for diabetes, agree that NIDDM is serious, the effort put in to achieving tight control is justified and there is a psychosocial impact of diabetes on patients, than patients.

Table 5: ANOVA analysis of the Diabetes Attitudes Scale patient and parent scores

Subscale	N	Mean	Standard Deviation	F	P
Need for Special Training	Patient: 98	4.15	0.558	11.995	0.001*
	Parent: 94	4.4	0.43		
Seriousness of NIDDM	Patient: 98	3.54	0.495	56.71	0.000*
	Parent: 94	4.08	0.497		
Value of Tight Control	Patient: 98	3.696	0.458	46.5	0.000*
	Parent: 94	4.12	0.411		
Psychosocial Impact of DM	Patient: 98	3.99	0.66	25.49	0.000*
	Parent: 94	4.4	0.46		
Patient Autonomy	Patient: 98	3.85	0.46	1.786	0.183
	Parent: 94	3.93	0.42		

DISCUSSION

This was a cross-sectional study comparing patient and parent perceptions of type 1 and type 2 diabetes and how it relates to metabolic control, quality of life and depression. Results of this study showcase that patient and parent perceptions differ in areas of diabetes care including the amount of value placed on having tight control of blood sugars. Parents scored significantly higher than patients on value of tight blood sugar control. Interestingly, while patients scored lower on value of tight blood sugar control than parents, they were still able to accurately assess their metabolic control based of hemoglobin A1c. Patients with higher hemoglobin A1c's rated their diabetes control as less well controlled than those who had lower hemoglobin A1c's which is an indicator of better metabolic control. This is similar to results found in the study by Fortenberry, et al. (2014) in that patients were able to identify behaviors of successful self-management and greater understanding of diabetes the longer they were diagnosed with diabetes and older they were but this was not necessarily reflected with better metabolic control. Nardi, Zucchini, D'Alberton, Salardi, Maltoni, Bisacchi, Elleri, and Cicognani, (2008) also had similar results showing that longer duration of diabetes correlated with worse hemoglobin A1c levels along with worse quality of life per parent report.

Our results also show a correlation with length of time since diagnosis and hemoglobin A1c in that the longer the patient was diagnosed with diabetes, the higher their hemoglobin A1c's trended. The relationship between length of time since diagnosis and hemoglobin A1c could also be a reflection of newly diagnosed patient's pancreases often maintaining a small level of insulin production called the honeymoon phase. As they get farther from diagnoses the body's ability to produce any exogenous insulin declines until there is none left, which can contribute to higher hemoglobin A1c levels if diabetes management does not increase to reflect the insulin needs of the body. Declining metabolic control as length of diagnosis increases may also be related to increased independence of adolescents with diabetes cares as they become older and more autonomous. As adolescents are learning how to self-manage they may have a greater understanding of what optimal diabetes control looks like but may need more time to develop successful self-management behaviors that lead to desirable metabolic control. Decreases in parental involvement in diabetes cares as adolescents become more autonomous and subsequent decline in adolescent adherence has been observed in the literature by Wiebe, et al., (2014). This decline in parental involvement, while natural, may also explain results of the PedsQL in the subscales of Communication. Results of the parent scores showed they believed their children with decreased ability to communicate diabetes concerns to health care providers than their children scored themselves as having. Patient's scores for Worry on the PedsQL showed that this aspect of their quality of life was most impacted overall with the lowest scores. This result is different than what Abdul-Rasoul, AlOtaibi, Abdulla, Rahme and AlShawaf (2013) found in a study comparing patient and parent report of children with type 1 diabetes quality of life. In their research they found that patient report of Worry was higher than parent report of worry (69.9+/-11.1 vs 59.8 +/-10.2, p=0.0001) (Abdul-Rasoul. AlOtaibi, Abdulla, Rahme & AlShawaf, 2013). Interestingly, their research showed that parent scores were always lower than patient scores, which is dissimilar to results of our study. This could be due to the difference in location as this study was performed in adolescents in Kuwait.

There was a significant negative correlation found in patient’s PedsQL results and hemoglobin A1c showing that the higher their hemoglobin A1c the lower their scores on the PedsQL indicating lower quality of life. Wagner, Muller, Godeffroy, Von Sengbusch, Hager, and Thyen (2005) found similar results in that poorer metabolic control may lead to lower quality of life scores.

Results of the depression screen in this study are similar to the results of Gutierrez and Long (2011), with 14% of patient’s having a positive screen compared to 11% positive depression screen. These results are higher than rates of positive depression screen seen nationally, which as reported by Siu (2015) is 8% for adolescents reporting major depression in the past year. Screening for depression continues to be a critical component of comprehensive diabetes care in pediatrics.

Strengths of this study include the use of validated questionnaires and tools to assess patient and parent perceptions including the PedsQL, and the Diabetes Attitudes Scale. The sample population appears to be diverse in relation to variability of hemoglobin A1c values. Limitations of this research include a small sample size of 98 patients and 94 parents and with the majority of patients having a diagnosis of type 1 diabetes and only four patients with type 2 diabetes. The small number of type 2 diabetes patients makes it challenging to generalize these results to all type 2 diabetic patients. Demographics of study participants was limited to age, sex. The Children’s Wisconsin Diabetes Clinic does have a diverse demographic and this information may have been beneficial to examine if results could be extrapolated to various demographics. The cross sectional study design does not allow one to draw clear conclusions of variables. The amount of question’s that the patient’s had to answer was high, which may have lead some patients to simply select answers to complete the study instead of taking the time to thoughtfully interpret the questions asked of them. In addition, the questions asked of parents did not include whether the parent felt like their child's diabetes was well controlled. This information would have been valuable to compare to patient's assessment of their metabolic control.

Implications and Future Directions

The results from this research are helpful for current medical providers, nurses, and dietitian's working with patients with diabetes and their parents. One can find comfort in the idea that pediatric patients with diabetes can understand and accurately assess their metabolic control. However, it remains important to continue to motivate patients to improve metabolic control to prevent future complications. Knowing that patients can identify accurately that their diabetes may not be optimally controlled based off hemoglobin a1c is the first step in addressing ways in which a patient and or family can make realistic and successful changes to improve metabolic control.

The PedsQL results show some potential areas of improvement when providing diabetes care. Parent responses revealed the thought that their children could not communicate as openly with providers about their diabetes. This is an area that healthcare providers can take into consideration when working with patients and families with diabetes. Having methods to support open communication and increase the dialogue in visits may help parents feel more confident in their child's ability to communicate with health care providers about their diabetes. In addition, parents felt as though their children had less worries about their diabetes including blood sugar fluctuations and future complications from diabetes. This may be a reflection of what parents are hearing from their children outside of clinic visits and could be another area in which health care providers working with patients who have diabetes may be able to provide more direct strategies to prevent large blood sugar swings and continue to discuss optimal blood sugar control to prevent future complications. Previous research regarding communication between children and parents around major complications from diabetes has been performed with results concluding frequent positive family communication about major complications leading to better patient adherence (Wysocki, Lochrie, Antal, & Buckloh, 2011). These results indicate that both parent and patient concerns about worrying and communication on the PedsQL can be improved with continued open communication about major complications, not necessarily related to overall knowledge of major complications. Providers working with diabetes patients can be a facilitator to improve conversations in clinic visits that promote healthy conversation around complications and decrease use of scare tactics around developing future major complications if a patient has suboptimal diabetes control. In addition to open and positive conversations diabetes technology has the capacity to improve self-management of diabetes. Tools such as continuous glucose monitors will continue to help with monitoring blood sugars and as this technology continues to evolve and become more accessible more patients will continue to be interested in using it. Future technologies in diabetes management will continue to be critical for health care providers to keep families informed about tools to support successful diabetes self-management.

Future studies utilizing a longitudinal design with additional follow up will help further support determining how perceptions of illness may play a role in successful self-management strategies and the relationship between quality of life and depression during the time of adolescence. This data is necessary to support patients during a vulnerable time full of changes and growing autonomy. Longitudinal study designs with multiple points of follow up will also help determine changing attitudes of parents and their children take more control over the management of their diabetes.

In conclusion, this study showed that adolescents have the ability to accurately identify the control of their diabetes based off hemoglobin A1c and that there is a relationship with length of diagnosis and metabolic control. Parents attitudes towards tight control of blood sugars are more agreeable than patient's. Patients had the lowest scores on the PedsQL on the subscale Worry indicating that blood sugar fluctuations and concerns about complications plays a large role in their overall quality of life. Parents identify that they feel like communication with healthcare providers is more challenging than patients identify based off PedsQL results. There is a relationship between patient's quality of life and hemoglobin A1c confirming that better metabolic control leads to improved quality of life.

BIBLIOGRAPHY

Abdul-Rasoul, M., AlOtaibi, F., Abdulla, A., Rahme, Z., AlShawaf, F. (2012). Quality of Life of Children and Adolescents with Type 1 Diabetes in Kuwait. *Medical Principles and Practice. 22*,379-384. Doi: 10.1159/000347052

Abubakari, A., Cousins, R., Thomas, C., Sharma, D., Naderali, E. K. (2015). Sociodemographic and clinical predictors of self-management among people with poorly controlled type 1 and type 2 diabetes: The role of illness perceptions and self-efficacy. *Journal of Diabetes Research.* 1-12.

American Diabetes Association. Classification and Diagnosis of Diabetes. Sec. 2. In Standards of Medical Care in Diabetes (2016). *Diabetes Care,40*(Supplement 1). doi:10.2337/dc17-s005

American Diabetes Association. Classification and Diagnosis of Diabetes. Sec. 2. In Standards of Medical Care in Diabetes (2018). *Diabetes Care, 41*(Supplement 1)S13-S27.

American Diabetes Association. Comprehensive Medical Evaluation and Assessment of Comorbidities. Sec. 3. In Standards of Medical Care in Diabetes (2018). *Diabetes Care, 41*(Supplement 1)S28-S37.

American Diabetes Association. Lifestyle Management. Sec. 4. In Standards of Medical Care in Diabetes (2018). *Diabetes Care, 41*(Supplement 1)S55-S64.

American Diabetes Association. Children and Adolescents. Sec. 12. In Standards of Medical Care in Diabetes (2018). *Diabetes Care, 41*(Supplement 1)S126-S136.

Anderson, R. M., Fitzgerald, J.T., Funnell, M. M., Gruppen, L. D. (1998). The third version of the diabetes attitude scale. *Diabetes Care, 21*(9), 1403-1407.

Bernstein, C. M., Stockwell, M. S., Gallagher, M. P., Rosenthal, S. L., & Soren, K. (2013). Mental health issues in adolescents and young adults with type 1 diabetes: Prevalence and impact on glycemic control. *Clinical Pediatrics,52*(1), 10-15.

Bond, G. G., Aiken, L. S., & Somerville, S. C. (1992). The health belief model and adolescents with insulin-dependent diabetes mellitus. *Health Psychology,11*(3), 190-198. doi:10.1037//0278-6133.11.3.190

Chiang, J. L., Kirkman, S., Laffel, L.M.B., Peters A. L. (2014). Type 1 diabetes through the life span: A position statement of the american diabetes association. *Diabetes Care,37*, 2034-2054. doi: 10.2337/dc14-1140

Gutierrez, J., & Long, J. A. (2011). Reliability and validity of diabetes specific health beliefs model scales in patients with diabetes and serious mental illness. *Diabetes Research and Clinical Practice,92*(3), 342-347.

Fortenberry, K. T., Berg, C. A., King, P. S., Stump, T., Butler, J. M., Pham, P. K., & Wiebe, D. J. (2014). Longitudinal trajectories of illness perceptions among adolescents with type 1 diabetes. *Journal of Pediatric Psychology,39*(7), 687-696.

Harvey, J.N. (2015). Psychosocial interventions for the diabetic patient. *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy.8,* 29-43.

Hood, K.K., Anderson, B.J., Butler, D.A., & Laffel, L.M.B. (2007). Updated and revised diabetes family conflict scale. *Diabetes Care.30*(7), 1764-1769.

Hullmann, S.E., Ryan, J.L., Ramsey, R.R., Chaney, J.M., Mullins, L.L. (2011). Measures of general pediatric quality of life. *Arthritis Care & Research,63*(11)S420-S430.

Mahan, L. K., & Escott-Stump, S. (2008). *Krause's Food & Nutrition Therapy*. St. Louis, MO: Saunders.

Mayer-Davis, E. J., Lawrence, J. M., Dabela, D., Divers, J., Isom, S., Dolan, L., Imperatore, G., Linder, B., Marcovina, S., Pettitt, D. J., Pihoker, C., Saydah, S., & Wagenknecht, L. (2017). Incidence trends of type 1 and type 2 diabetes among youths, 2002–2012. *New England Journal of Medicine,377*(3), 301-301. doi:10.1056/nejmc1706291

Martire, L.M., & Helgeson, V.S. (2017). Close relationships and the management of chronic illness: Associations and interventions. *Am Psychol,72*(6), 601-612. Doi:10.1037/amp0000066

Mensing, C., McLaughlin, S., & Halstenson, C. (2011). *The Art and Science of Diabetes Self-management Education Desk Reference second edition*. Chicago, IL: American Association of Diabetes Educators.

Nardi, L., Zucchini, S., D'Alberton, F., Salardi, S., Maltoni, G., Bisacchi, N., Elleri, D., & Cicognani, A. (2008). Quality of life, psychological adjustment and metabolic control in youths with type 1 diabetes: a study with self- and parent-report questionnaires. *Pediatric Diabetes,9*, 496-503.

Karimy, M., Araban, M., Zareban, I., Taher, M., & Abedi, A. (2016). Determinants of adherence to self-care behavior among women with type 2 diabetes: An explanation based on health belief model. *Medical Journal of the Islamic Republic of Iran,30*(368).

Patino, A. M., Sanchez, J., Eidson, M., & Delamater, A. M. (2005). Health beliefs and regimen adherence in minority adolescents with type 1 diabetes. *Journal of Pediatric Psychology,30*(6), 503-512.

Pociot, F., & Lernmark, Å. (2016). Genetic risk factors for type 1 diabetes. *The Lancet,387*(10035), 2331-2339. doi:10.1016/s0140-6736(16)30582-7

Polonsky, W. (2000). Understanding and assessing diabetes-specific quality of life. *Diabetes Spectrum.13*(1). 36-41.

Raosoft. (2004). *Sample Size Calculator.* Raosoft, Inc. https://raosoft.com/samplesize.html

Rewers, M., & Ludvigsson, J. (2016). Environmental risk factors for type 1 diabetes. *The Lancet,387*(10035), 2340-2348. doi:10.1016/s0140-6736(16)30507-4

Sui, A. (2015). Screening for Depression in children and adolescents: US preventative services task force recommendation statement. *Pediatrics, 137*(3). Doi: 10.1542/peds2015-4467

Szablewski, L. (2014). Role of immune system in type 1 diabetes mellitus pathogenesis. *International Immunopharmacology,22*(1), 182-191. doi:10.1016/j.intimp.2014.06.033

Vanzini, H., & Barati, M. (2014). The Health Belief Model and Self-Care Behaviors among Type 2 Diabetic Patients. *Iranian Journal of Diabetes and Obesity,6*(3). 107-113.

Wiebe, D.J., Chow, C.M., Palmer, D.L., Butler, J.M., Osborn, P., Berg, C.A., (2014). Developmental processes associated with longitudinal declines in parental responsibility and adherence to type 1 diabetes management across adolescence. *Journal of Pediatric Psychology, 39*. 532-541. Doi:10.1093/jpepsy/jsu006

Wit, M. D., Delemarre-Van De Waal, H., Bokma, J. A., Haasnoot, K., Houdijk, M. C., Gemke, R. J., & Snoek, F. J. (2008). Monitoring and discussing health-related quality of life in adolescents with type 1 diabetes improve psychosocial well-being. *Diabetes Care,31*(8), 1521-1526.

Wysocki, T., Lochrie, A., Antal, H., Buckloh, L. (2011). Youth and parent knowledge and communication about major complications of type 1 diabetes. *Diabetes Care,34*(8),1701-1705. Doi.org/102337/dc11-0577

Zaccardi, F., Webb, D.R., Yates, T., & Davies, M.J. (2015). Pathophysiology of type 1 and type 2 diabetes mellitus: a 90-year perspective. *Postgrad Med J,* 92, 63-69. Doi:10.1136/postgradmedj-2015-133281