The Impact of Accurate Knowledge on the Adaption of People with Diabetes

by

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Dedication

For Dillon – my rock, inspiration, best friend, and future husband – thank you for all that you are and all that you do. I will love you forever and always.

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I would like to acknowledge and thank all the many people without whose support and encouragement this project would not have been possible. Specifically, I would like to thank Dr. Michelle Leonard and Dr. Nancy Wrobel for their patience and dedication to this project. Your mentorship has taught me so much throughout this process, and without your support and encouragement this project would not have shined as brightly as it does. I would also like to thank all the faculty that I have had the privilege of learning from over the course of both my bachelor's and master's degrees. Beginning this program and transitioning through the recent pandemic, has brought its share of challenges and yet it has also ignited a strength within me that I am eternally indebted for. With the additional support of my cohort, my experiences over the past three years have taught me how to be comfortably authentic with my own diagnoses and to keep pursuing my dream of integrating diabetes behavioral care throughout my career as a clinical health psychologist. I appreciate their own perseverance and motivation through all the changes that have occurred in our years together. I would also like to thank my parents, family, and friends. The sacrifices that you have had to make to support me through this program do not go unnoticed and I am forever grateful for every single one of you. Lastly, I'd like to thank my fiancé, Dillon, for his unwavering and unconditional love. Your belief in me and your support in my professional accomplishments have made each challenge easier and every achievement more exciting. I truly could not have done this without you.

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Abstract

On average, 1.5 million Americans are diagnosed with diabetes in the United States each year (CDC, 2020). That's why it's imperative to understand the factors associated with successful self-management and treatment adherence for individuals with diabetes. Current literature supports the connections found between the accuracy and source of diabetes-related knowledge as well as their association with relevant health outcomes (e.g., self-efficacy/empowerment and diabetes-related distress; Heise et al., 2022); however, minimal research has been conducted that considers the complex relationships between self-efficacy and distress. With increasing access to technology, it's also apparent that diabetes knowledge is readily available to patients and yet the accuracy of this information can elicit confusion for individuals with diabetes when they attempt to utilize this information within their self-management program. This study sought to help identify knowledge to positively improve diabetes care and aid health professionals to better support their patients. Thus, the relationship between diabetes-specific knowledge, empowerment, and distress were examined, with most findings having significant variation between the accuracy of participant knowledge and its association with empowerment and distress. The results of this study highlight the alarming discrepancies found in the relevant diabetes information that individuals have, impacting their ability to successfully manage their disease. The information gathered from this study promotes future research and analyses for more integrative approaches to diabetes education as well as improvements to the health system more broadly (e.g., healthcare providers and diabetes education courses).

Keywords: Diabetes, psychology, knowledge, empowerment, distress

Chapter One

Introduction

It is unavoidably apparent that the diabetes crisis has become a global health concern as 537 million people aged 20 to 79 years have diabetes mellitus worldwide (International Diabetes Federation [IDF], 2021). Diabetes, as a chronic health condition, requires an individual to engage in a certain level of self-management and proactive self-care (Karimy et al., 2018). This level of care necessitates that information about the illness and treatment be not only available, but also be accurate, to patients who suffer with diabetes. A newer theoretical perspective based on empowerment, highlights the role that access to and accuracy of information about diabetes can both directly and indirectly impact negative diabetes outcomes, including poor glycemic control, medication adherence, and well-being. Therefore, this study is aimed at understanding how the manner in which individuals obtain knowledge about their diabetes, their beliefs about diabetes care, and the accuracy of diabetes related information are associated with perceived self-efficacy and empowerment of individuals with Type 1 and Type 2 Diabetes. The study will also examine how knowledge and self-efficacy/empowerment are subsequently associated with diabetes related distress. Moreover, this paper will focus on identifying and understanding the gaps in current diabetes self-management education and support services with the goal being to ultimately provide additional insight for further research to improve diabetes management, treatment compliance, and overall health outcomes of individuals with diabetes.

Defining Diabetes

The American Diabetes Association defines diabetes mellitus as, “A group of metabolic diseases characterized by hyperglycemia resulting from defects in insulin secretion, insulin action, or both” ([ADA], 2009). Diabetes mainly affects hormone production in the pancreas gland that produces glucagon and insulin. This plays a vital role in converting food, such as sugars and starches, into energy for various cells throughout the body. Furthermore, diabetes is an autoimmune disorder in which the immune system attacks the islet beta cells, or β-cells, of the pancreas, influencing hormone production which disrupts the body’s glucose regulation. Glucose dysregulation can cause two types of blood sugar issues in individuals with diabetes: one is hypoglycemia that occurs when blood glucose levels are too low, the other is hyperglycemia that can occur when blood glucose levels are too high. It is important to note that either of these symptom presentations can occur in conjunction with one another or as individual issues. Aside from prediabetes, in which above normal blood glucose levels gradually develop and become more severe over time, there are three primary forms of diabetes, including Type 2, Type 1, and Gestational Diabetes (Mayo Clinic, 2020).

Prevalence

On average, 1.5 million Americans are diagnosed with diabetes in the United States each year, with incidence rates higher among adults aged 45 years and older as compared to adults aged 18 to 44 years (CDC, 2020). According to the Centers for Disease Control and Prevention ([CDC], 2020), over 122 million Americans (10.5% of the population) have diabetes (34.2 million) or prediabetes (88 million). In the United States, diabetes is the third most common chronic illness, and the seventh leading cause of death, with 84,946 known deaths per year. As previously stated, the total cost of diagnosed diabetes in the United States was $327 billion of which $237 billion was equated to direct medical costs and $90 billion to reduced productivity.

Approximately 1 in 2 (240 million) adults worldwide and 7.3 million Americans (21.4%) have undiagnosed diabetes (CDC, 2020; IDF, 2021). Misdiagnosis is also common as research conducted by Lusignan et al. (2010) suggests that a substantial number of Americans are misdiagnosed with diabetes every year.

Type 1 Diabetes

Type 1 Diabetes (T1D), also known as insulin-dependent, was called juvenile-onset or juvenile diabetes in the past due to its typical appearance during childhood or adolescence (Mayo Clinic, 2020). However, development has also been noted in adults. This form of diabetes affects 1.6 million Americans (ADA, 2018) and results from the rapid or gradual cell-mediated destruction of islet β-cells in the pancreas over time and usually leads to absolute insulin deficiency (ADA, 2009). Symptom presentation often mimics the flu and includes, but is not limited to, excessive thirst and urination, craving for sweets, unexpected weight loss, extreme fatigue, irritability, and mood swings. These symptoms are related to the body's inability to metabolize glucose for energy, forcing the body to begin feeding off its fats and proteins.

Although there is much debate regarding its clinical categorization, Type 1.5, or Latent Autoimmune Diabetes in Adults (LADA), is considered by many scholars as a subgroup of T1D (Palmer et al., 2005). Individuals with Type 1.5 diabetes are typically adults aged 30 years and older that have increased insulin resistance, the accumulation of islet autoantibodies, and noted reactions between t-cells and islet proteins like T1D. The autoimmune nature of both T1D and Type 1.5 diabetes supports the categorization of LADA as a subgroup of T1D. However, some researchers have discovered a small group of patients in which the reaction between islet proteins and t-cells are present, but who are negative for islet autoantibodies. Therefore, it's quite

apparent that there's still a vast area of confusion surrounding this clinical distinction of Type 1.5 diabetes with regards to T1D and Type 2 Diabetes (T2D) (Palmer et al., 2005).

Type 2 Diabetes

According to the ADA (2018), T2D is the most prevalent type of diabetes as it affects 25.2 million Americans and approximately 95% of Americans with diabetes have T2D (CDC, 2020). T2D was previously termed non-insulin diabetes or adult-onset diabetes; however, in recent years, it has begun appearing in children as well (Dündar & Akıncı 2022). T2D results from various forms of insulin resistance where the pancreas fails to produce enough insulin, is insensitive to insulin, or both. This glucose intolerance, in turn, causes a decrease in the total number of insulin receptors located in the nearby target cells. Like T1D, symptoms of T2D diabetes often include, but are not limited to frequent urination, fatigue, slow healing of cuts and bruises, mouth dryness, fruity-smelling breath, irregular menstruation, and pain or cramps in the legs, feet, and fingers.

Gestational Diabetes

The third most common form of diabetes, known as gestational diabetes, affects almost 10% of total pregnant women in the United States each year (CDC, 2020). Gestational diabetes occurs initially during pregnancy and causes high blood sugar that can influence the pregnancy and the unborn child's overall health (Mayo Clinic, 2020). Screening for this type of diabetes typically occurs during the second trimester or between 24 and 28 weeks of pregnancy; however, those with a higher risk of diabetes may require earlier screening typically conducted during the first prenatal doctor's visit. It's important to note that gestational diabetes is an acute diagnosis with the women's blood sugar levels returning to normal soon after delivery; however, studies suggest that the gestational diabetes diagnosis may put women at an additional risk of developing

T2D after childbirth (Mayo Clinic, 2020) and their children are also at increased potential for their own diabetes diagnosis in the future.

Other Types of Diabetes

An estimated 1 to 5% of all diagnosed cases of diabetes include other less prevalent types of diabetes including monogenic diabetes syndromes, such as maturity-onset diabetes of the young (MODY) and neonatal diabetes, diseases of the exocrine pancreas, such as cystic fibrosis and pancreatitis, and drug or chemical-induced diabetes, such as glucocorticoid use in HIV/AIDS treatment or after organ transplantation (ADA, 2014). Current literature suggests the potential for additional research into these other types of diabetes such as Type 3; however, these are not yet recognized by major diabetes and disease-related organizations (Maddaloni, & Pozzilli, 2014). With the potential for additional types of diabetes, misdiagnosis is possible (Lusignan et al., 2010) and studies have suggested that many individuals diagnosed with T2D have been misdiagnosed and may instead have Type 1.5 diabetes (Appel, Wadas, Rosenthal, & Ovalle, 2009). A limited understanding or misdiagnosis may negatively impact health outcomes due to the additional health complications related to inadequately prescribed treatment.

Treatment Issues: Diabetes Self-Management Education and Support (DSMES) Services as an Answer

Although there are different types of diabetes as outlined above, treatment approaches that are implemented in the management plan are often similar. As part of the standards of medical care, after the initial diabetes diagnosis, an evaluation is conducted, and a diabetes management plan is then determined by the physician-coordinated healthcare team (ADA, 2008). Ideally, this management plan should be formulated as an "individualized therapeutic alliance" with the patient, their family, their healthcare team, and include adequate education and problem-

solving skills regarding various aspects of diabetes self-management. Effectiveness of the management plan is determined by an assessment of glycemic control that includes the patient's daily self-monitoring of their blood glucose as well as quarterly HbA1c measurements conducted by the healthcare team. Moreover, glycemic control goals are fundamental to the success of the diabetes management plan (Mayo Clinic, 2020) and should be individualized in nature (ADA, 2008).

Education and Knowledge

For chronic diseases that require elements of self-management, knowledge is key to understanding how a disease functions and how self-management behaviors can improve overall health outcomes (Dawson et al., 2017; See Figure 2). Diabetes knowledge acts as an essential precondition for positive health outcomes and self-care activities (Hailu et al., 2019). Increasing access to diabetes-related information and assessing the educational level of an individual is an important factor in self-management as knowledge plays a vital role in increasing treatment adherence and shared decision making (Xinjun et al., 2019). Moreover, current literature suggests a significant correlation between diabetes knowledge and HbA1c levels (Hailu et al., 2019). This is supported by the association between health literacy rates and disease knowledge as these are positively correlated with poor glycemic control of an individual (Powell et al., 2007).

Knowledge of diabetes as a chronic medical illness includes information on the biological processes involved in diabetes, essential information about self-management and self-care, such as barriers to care, and how to maintain quality of life following a diagnosis of diabetes. These elements of psychoeducation are essential in a patient's understanding and maintenance of their disease. When an individual is provided with appropriate information by their healthcare team,

they are more capable of making their own decisions regarding the development, modification, and facilitation of their treatment plan. For instance, patients with diabetes need to have knowledge that the primary goal for diabetic treatment is to maintain glycemic control to keep safe and healthy blood glucose levels, which are self-checked (Rakhis et al., 2022). Moreover, patients need to understand how the two most prescribed medications, rapid-acting bolus or long-acting basal insulins, are administered and which medication to use when.

Not only do individuals with diabetes need to have a sound understanding of the biological aspects of their diabetes and treatment, but they also need to understand that their health outcomes are largely reliant on self-management. The problem at hand is that there are many long-term benefits to taking care of diabetes, but few immediate ones (Polonsky, 1995). Polonsky (1995) explores barriers at multiple levels (e.g., personal, interpersonal, and environmental) to diabetes self-management and positive outcomes. Individuals with diabetes often have personal barriers including chronic depression, poor coping styles, eating disorders, lack of diabetes-specific knowledge, inaccurate health beliefs, negative feelings about diabetes, fear of hypoglycemia, fear and frustration about weight gain, and unrealistic and unclear expectations about self-care (Sartorius, 2022).

This is supported by Aikens (2012) and Nicolucci and colleagues (2013) who suggest an association between suboptimal self-management and diabetes-related distress among people with diabetes. Moreover, interpersonal barriers including family conflict, too much or little support, family confusion about self-care responsibilities, and poor patient-provider relationships have been identified. People with diabetes may also encounter environmental barriers such as chronic life stressors, competing priorities, and financial burdens of diabetes care (Polonsky,

1995). These barriers just highlight the need to provide a sense of empowerment/efficacy for patients with diabetes.

Patients and health care providers both need to understand the course of diabetes and that "outcomes" could include elements of quality of life. People with diabetes often report feelings of negativity regarding their diabetes and the disease's impact on many aspects of their daily life (Nicolucci et al., 2013). In fact, the Agency for Healthcare Research and Quality (2015), diabetes-specific outcomes include behavioral, clinical, and health outcomes. Behavioral outcomes include changes in physical activity, nutritional intake, medication adherence (e.g., self-regulation of insulin based on diet and physical activity), and treatment compliance (e.g., self-monitoring blood glucose and medication).

Clinical outcomes include glycemic control (e.g., HbA1c), change in body composition, episodes of severe hypoglycemia, treatment for hyperglycemia, control of blood pressure and lipids, sleep quality, and development of depression or anxiety. Health outcomes include quality of life, development of micro- and macrovascular complications, and mortality (Agency for Healthcare Research and Quality, 2015). Many times, patients, or providers themselves, will focus on clinical outcomes while knowledge about the patient caring for themselves or managing the distress of a chronic illness is minimized. Diabetes is a patient-managed disease in which an individual with diabetes should be able to identify and implement their own treatment goals

As can be seen, the current literature suggests that diabetes-related knowledge can play a pivotal role in the overall success of DSMES services throughout the course of diabetes treatment; however, it is often neglected (Phillips et al., 2018). Research suggests that fewer than 50% of individuals with diabetes attend diabetes education or behavioral change classes, and behavioral interventions are quite often not integrated into diabetes care (Hunter et al., 2017).

Therefore, the lack of diabetes education and knowledge among people with diabetes indicates an urgent need for further development in patient education efforts to improve health outcomes and decrease diabetes-related health care costs (Phillips et al., 2018). The inconsistency of DSMES services is alarming as the ability of a patient with diabetes to improve their overall adherence to their treatment plan is dependent on the enthusiasm and periodic reinforcement provided by their healthcare team (Gómez-Velasco et al., 2019). According to Grant et al. (2017), limited time available within primary care appointments is problematic as physicians only have time to explain basic information on living with diabetes to newly diagnosed patients. Current literature suggests that the short duration of time within these appointments may be associated with lower self-confidence and self-efficacy because patients are too intimidated to discuss their fears, self-care needs, and difficulty complying with their treatment regimen.

Empowerment and Self-Efficacy

As a part of DSMES care, research by Funnel and Anderson (2004) supports the implementation of diabetes empowerment programs as a specific intervention for diabetes management. According to WHO (2008), empowerment can be described as, "A process in which people gain control over their decisions and actions affecting health." Patients are empowered when they have the appropriate attitudes, knowledge, skills, and self-awareness to maintain their diabetes treatment program throughout their daily lives. This is supported by research conducted by Gómez-Velasco et al. (2019) that suggest that individuals are empowered when they have adequate knowledge to make rational decisions, gain access to resources that help implement their decisions, and provide sufficient experience for them to evaluate the effectiveness of those decisions. A patient's sense of empowerment can be directly associated with the increased self-efficacy of that individual. Work by Hernandez-Tejada et al. (2012)

found a positive association between diabetes empowerment and treatment adherence, knowledge, and self-care behaviors. Moreover, Knowles et al. (2020) emphasizes the duality between empowerment and self-efficacy as an essential part of the treatment process to promote positive diabetes-related health outcomes. This in turn leads to increased treatment adherence and overall quality of life as well as lowering the risk of diabetes related complications (Ho et al., 2010; See Figure 1).

Diabetes empowerment group programs build a sense of empowerment for individuals, which ultimately helps patients achieve successful self-management and improve diabetes-related health outcomes (Gómez-Velasco et al., 2019; Ho et al., 2010). Moreover, these programs enhance the adjustment process by promoting an environment characterized by psychological safety, warmth, collaboration, and respect (Gómez-Velasco et al., 2019). Using this type of health enhancing intervention also increases autonomy and patient participation in the adoption of a healthy lifestyle. This in turn allows for individuals with diabetes to take responsibility for their care and garner a sense of self-efficacy to improve health outcomes and reduce overall healthcare costs, which is consistent with a DSMES approach.

Research conducted by Ho et al. (2010) synthesized nine qualitative studies to elicit a deeper understanding of client perceptions regarding an effective empowerment strategy for diabetes self-management. Using Pender's Health Promotion Model, their study supported the urgency of health care professionals to assimilate and address modifiable behavior-specific variables (e.g., checking blood sugar, physical activity, nutritional intake monitoring) as it relates to diabetes empowerment. This in turn highlights the need for an overall shift in attitude for both patients and healthcare professionals to use empowerment to positively influence an individual's compliance with their diabetes self-management program. Therefore, according to Ho et al.

(2010), “an effective empowerment strategy would be to use activity-related affect, as well as interpersonal and situational influences, as a means of facilitating and enhancing clients’ health-promoting behaviors” (p. 259).

One way that empowerment has been conceptualized in the literature is through the variable of perceived self-efficacy (Ho et al., 2010). According to Bandura’s Social Cognitive Theory, self-efficacy is characterized by the confidence a person needs to effectively perform and engage in a particular health behavior is influenced by their perceived level of overall ability (Clipper et al., 2018). Specifically, self-efficacy focuses on psychosocial issues that include managing stress, obtaining family support, negotiating with healthcare professionals, and dealing with uncomfortable emotions (Anderson et al., 2000). Moreover, Anderson et al. (2000) suggest that perceived self-efficacy relates to the willingness and ability of people to engage in behavioral challenges, including preventative and disease management behaviors.

Self-efficacy is based on the interaction between personal, behavioral, and environmental factors that impact health and chronic disease. Diabetes-specific behaviors, such as finger-pricking and syringe administered insulin, can often elicit strong emotions and feelings surrounding treatment adherence given the complex nature of application required throughout the self-management program. Alternatively, a lack of self-efficacy/empowerment can negatively influence an individual’s behaviors included in the maintenance of their diabetes management program (Silveira et al., 2019). In addition, research suggests that self-efficacy should be assessed and monitored during diabetes self-management interventions (Jiang et al., 2019).

Summary and Conclusions

Diabetes is a global health crisis and estimates suggest that the number of individuals with diabetes will continue to expand (IDF, 2021). The current literature highlights the importance of knowledge and feelings of empowerment/self-efficacy in comprehensive diabetes care; however, research is lacking in these areas. Specifically, there are limitations between these associations with consideration of participant sociodemographic characteristics (e.g., Gender, Household Size). Research in diabetes care is essential as healthcare professionals need to be able to identify the potential barriers that may interfere with the induction of empowerment within a patient's ability to adhere and comply with their diabetes self-management program. Although, DSMES are the standard of care (Phillips et al., 2018), these services are often lacking or limited based on the current health care system. Moreover, with increasing access to technology, diabetes knowledge is now readily available to patients via the internet and various social media sources. However, the density and accuracy of this accessible information can elicit confusion for diabetic individuals when considering and applying this to their specific self-management programs.

Therefore, this study seeks to provide an increased understanding of a diabetic individual's access to knowledge, what diabetes management information is known and available, what information can be provided to enhance their overall sense of empowerment and self-efficacy surrounding their diabetes self-management treatment, and self-efficacy as it relates to increased knowledge regarding various diabetes management protocols. By identifying the various sources and accuracy of acquired knowledge and the association to empowerment, this project ultimately intends to help distinguish potential gaps in current and readily available diabetes-specific knowledge to positively improve diabetes care for individuals with diabetes and to aid health professionals to better support their patients with diabetes.

Based on the literature reviewed above, the following hypotheses can be made:

1. There will be a positive association between the accuracy of diabetes-knowledge and the self-efficacy/empowerment of individuals with diabetes.
    a. Sources of information will be explored as part of this analysis.
2. There will be a negative association between the accuracy of diabetes-knowledge and diabetes-related distress.
3. There will be a negative association between self-efficacy/empowerment and diabetes-related distress.
4. Self-efficacy/empowerment will be a mediator of the association between accurate diabetes-knowledge and diabetes-related distress.

Chapter Two

Methods

Participants

Data collection for this study utilized an online survey format. Participants were recruited via a Qualtrics link that was sent to the participant's email address from the Managed Research CloudResearch service. Using a sample size calculator with a power of .95 and a medium to small effect size, it was estimated that a sample size of 200 would result in enough power to reject an incorrect null hypothesis (Hernandez-Tejada et al., 2012). Inclusion and exclusion criteria required participants to be above the age of 18, able to read English, live in the United States, and have a current diagnosis of T1D or T2D. Due to the discrepancy between appropriate clinical distinctions of LADA, this study will categorize LADA within the context of T1D. Moreover, although more research is needed on less prevalent types of diabetes, the current study will focus on T1D and T2D. Participation was anonymous and any personal identifying information collected via Qualtrics and CloudResearch were de-identified and participants were only identified using a unique assignment identification (AID) value.

In total, 829 participants completed the study; however, 318 (M = 48.8; R = 21-86) were deemed appropriate based on the exclusion criteria and CloudResearch. Most participants identified as male (55.1%, n = 228), were reported living with one person (23.6%, n = 75), were married (58.5%, n = 186), worked a minimum of part-time (54.7%, n = 174), and reported having at least some college or technical school experience (77.7%, n = 247). Of the 318

participants who met inclusion criteria for the study, most participants had T2D (75.5%, n = 240) and the remaining participants had T1D (24.5%, n =78). Additional participant sociodemographic characteristics are detailed in Table 1 and 2.

Measures

Based on the literature reviewed above and the conceptualized model (Figure 1), the following constructs were measured for the purposes of this study.

Demographics Questionnaire

Participants were asked to complete a brief demographics questionnaire that utilized "Section I – Demographics" of the Diabetes Care Profile (DCP; Fitzgerald et al., 1996), except for items that asked about health insurance, birthdate, and zip code. These items were omitted due to inapplicability for purposes of this study and to protect patient anonymity. It should be noted that adjustments were made to the response options available for two items to increase gender and ethnic inclusivity. Participants were asked to respond to questions pertaining to their age, race/ethnicity, sex, education, income level, and housing, with diabetes-related questions referring to participants' specific diagnosis, duration, and blood sugar monitoring (i.e., frequency and record keeping history).

Knowledge

Simplified Diabetes Knowledge Scale.

The Simplified Diabetes Knowledge Scale (SDKS; Collins et al, 2011; Fitzgerald et al, 2016) consists of 20 items used to measure general knowledge of diabetes and can be administered for individuals with diabetes that do and do not require insulin as part of their medication treatment plan. The SDKS was developed from the Revised Diabetes Knowledge Scale (RDKS) in which the multiple-choice responses of the RDKS were replaced with "True",

"False", and "Don't Know" options. Apart from item 17 ('You realize just before lunch that you forgot to take your insulin before breakfast. What should you do now?'), all items from the RDKS have an equivalent item on the SDKS. This item was excluded as it could not be answered with a true/false format. Scores for the SDKS (omitting the non-core items) are calculated as the proportion of correct responses. The total knowledge score for this measure was created by summing the number of correct responses to each of the 20 items. If an item was answered incorrectly or the participant stated that they "did not know" it was marked as incorrect. This score was then turned into a percentage for ease of interpretation. The DSKS scale also showed strong reliability in the current sample ($\alpha = .71$).

Diabetes Knowledge Source Questionnaire.

A Diabetes Knowledge Source Questionnaire (DKSQ) was administered at the same time as the SDKS. Specifically, after each SDKS question the participant marked as either true or false, they were asked to identify where they learned this information from. The options were: Health Care Provider/Team, Diabetes Education Course(s), Online, Social Media, and Other. If a participant responded to the SDKS item with "don't know" the source questions were omitted. This measure was created for the purposes of this study. Research has suggested that providers are often a frequent source of information, but individuals with chronic conditions often seek information from family/friends and the internet to obtain health related information (Bruce et al, 2003; Fenwick et al, 2013; Tefera et al, 2019).

Self-Efficacy/Empowerment

Diabetes Empowerment Scale.

The Diabetes Empowerment Scale (DES; Andersen et al., 2000) is a six-point Likert type scale (5, 'strongly agree' to 1, 'strongly disagree') that consists of 28 items used to measure the

self-efficacy of people with diabetes. The DES contains three subscales that allow for the examination of underlying components related to psychosocial self-efficacy in diabetes (i.e., managing the psychosocial aspects of diabetes; assessing dissatisfaction and readiness to change; setting and achieving goals). It should be noted that one of the items for the DES was inadvertently left out of the online survey. The item that was left out stated, "I believe I know what helps me stay motivated to care for my diabetes". This item was part of the managing the psychosocial aspects of diabetes subscale. For the purposes of this study, the DES was scored without this item. Nonetheless the DES scale showed strong reliability in this sample ($\alpha = .95$).

Diabetes-Related Distress

Problem Areas in Diabetes Scale.

The Problem Areas in Diabetes (PAID; Welch et al., 1997) scale is a five-point Likert type scale (0, 'not a problem' to 4, 'serious problem') that consists of 20 items representing a unique area of diabetes-related distress. The PAID measures and describes a wide range of negative emotions related to diabetes (e.g., fear, anger, frustration, guilt, worry, and depressed mood) and takes approximately five minutes to complete. In addition, this scale covers a variety of emotional concerns and dietary problems and complications as they relate to diabetes (Lee et al., 2014). The total score is calculated by adding up the scores and multiplying them by 1.25, generating a total score between 0-100 in which higher levels of 40 or higher indicate greater emotional distress. The PAID scale showed strong reliability ($\alpha = .97$) in the current sample.

Diabetes Distress Scale.

The Diabetes Distress Scale (DDS; Polonsky et al., 2005) is a six-point Likert type scale (1, 'no problems' to 6, 'serious problems') that consists of 17 items reflective of physician-related distress and problems concerning diabetes self-management. Of the total 17-items, the

DDS is made up of four subscales: Emotional Burden (e.g., emotions related to the long-term demands for diabetes self-management such as feeling overwhelmed, frightened or fearful; 5 Items), Physician Distress (e.g., worries about health care and obtaining sufficient expertise, support and direction from health care providers; 4 Items), Regimen Distress (e.g., emotions related to poor diabetes self-management such as meal planning and physical activity; 5 Items), and Interpersonal Distress (e.g., emotions related to receiving sufficient support for their diabetes among family and friends; 3 Items). Additionally, the DDS scale showed strong reliability (α = .98).

Procedure

This study utilized online data collection. Participants were recruited via a Qualtrics link that was provided by Managed Research services of the CloudResearch platform. Once participants entered the Qualtrics link, they were then presented with a consent form section that detailed the purpose of this study, including estimated duration, anticipated risks and benefits, explanation of their right to withdraw at any time, and confidentiality. Those who chose to deny consent were thanked for their interest in the study and redirected to the corresponding CloudResearch link. Those who chose to provide consent proceeded to the initial study section of the demographic's questionnaire. Upon completion of the demographic questionnaire, participants then completed the Diabetes Empowerment Scale (DES), Problem Areas in Diabetes Scale (PAID), and Diabetes Distress Scale (DDS). Participants then completed the Diabetes Knowledge Test to assess their level of diabetes knowledge and completed a corresponding item of the Access to Diabetes Knowledge Evaluation in order to allow the participant to identify the source(s) in which they acquired their knowledge as described above. When participants completed the study, they received a debriefing form that provided a summary of the study and

additional resources available. Upon completion of the study, participants received compensation in the amount they agreed to with the CloudResearch platform through which they entered the survey. Payment was denied if participants were not able to correctly answer two attention check questions that demonstrated they were paying attention.

Data Analysis Plan

Study data was analyzed using the IBM Statistical Package for Social Sciences (SPSS; Version 28). Descriptive statistics were used to summarize participant data and responses to the four total scale scores: SDKS, DES, PAID, and DDS. To examine these scales by participant demographics, individual sample t-tests were used to compare total scale scores by sex, and marital status. One-way analysis of variance (ANOVA) was also used to compare scores between housing/residence, education, and employment. It should be noted that given the distribution of some of the demographic variables several categories had to be collapsed to obtain comparable sample sizes. To test hypotheses 1-3 (the bivariate associations between self-efficacy/empowerment, diabetes outcomes, and diabetes knowledge), Pearson correlations were conducted. Data on sources were collected in such a way that participants could list all the sources that they used so there were multiple sources indicated for each item on the knowledge questionnaire. Therefore, sources of information were explored using frequency distributions and associations were then examined as possible. The proposed mediation was tested using hierarchical linear regression analysis according to the procedures outlined by Baron and Kenny (Baron & Kenny, 1986).

Chapter Three

Results

Prior to any data analysis, data were checked for missing values and normalcy. There were no missing values on any of the items on the online survey, likely due to the online platform that was used. On individual study variables, there were several outliers noted on each of the measures. On the DDS there were 3 participants that were univariate outliers, on the DES 3 scores were outliers, and the PAID had 7 participants whose scores were indicative of univariate outlier status. Examination of the data for all these outliers, however, showed that only one participant's score was greater than 2.5 standard deviations from the mean. This individual's score was windsorized and the remainder of the data were kept in their original form. Analysis of multivariate outliers showed that there was a total of 18 multivariate outliers based on the Mahalanobis distance statistic with a chi-square critical value of 9.48. For the purposes of this study these participants were deleted.

Associations between demographic variables and study variables were conducted. First, correlations were run with age and study variables. As can be seen in Table 2, participant age was positively associated with knowledge and negatively associated with distress. Although diabetes duration did not show any significant associations to study variables, diabetes type was positively associated with knowledge ($t(316) = -1.865$, $p < .05$) and comparison of means indicated that those experiencing T2D ($n = 240$, $M = 0.607$, $SD = 0.163$) showed greater knowledge than those who reported having T1D ($n = 78$, $M = .567$, $SD = .148$). Diabetes type

was also positively associated with distress on the PAID ($t(316)=3.792$, $p < .001$) as those self-reporting T1D ($n = 78$, $M = 51.106$, $SD = 23.033$) showed greater distress than those reporting T2D ($n = 240$, $M = 37.87$, $SD = 28.017$). Similar positive associations were found when comparing diabetes type and the DDS ($t(316) = 4.192$, $p < .001$), as T1D ($n = 78$, $M = 3.391$, $SD = 1.429$) showed greater distress in those who reported T1D when compared to T2D ($n = 240$, $M = 2.253$, $SD = 1.282$). As shown in Table 3, those who reported daily blood glucose monitoring showed significant differences on levels of distress. Participants that reported daily blood glucose monitoring ($n = 264$, $M = 42.66$, $SD = 26.876$) showed more distress on the PAID ($t(316) = -2.290$, $p = .011$) and the DDS ($t(316) = -4.242$, $p = .008$) compared to those who don't monitor their blood sugar ($n = 54$, $M = 33,33$, $SD = 29.13$). However, there were no significant differences for diabetes knowledge ($t(316) = -1.410$, $p = .080$) or self-efficacy/empowerment ($t(316) = .742$, $p = .229$).

There were significant differences between gender groups on knowledge ($t(315)=-4.395$, $p < .001$) where women showed greater diabetes knowledge ($n = 159$, $M = 0.64$, $SD = 0.17$) than men ($n = 158$, $M = 0.56$, $SD = 0.15$). Results also suggested small, weak negative associations for gender and distress for the PAID ($r = -.111$, $n = 318$, $p < .05$) and the DDS ($r = -.103$, $n = 318$, $p < .05$). Those who were married ($n = 186$, $M = 0.592$, $SD = 0.154$) showed more distress on the DDS ($t(316) = -3.458$, $p < .001$) and the PAID than those who were not married ($n = 132$, $M = 0.605$, $SD = 0.170$). Similar significant differences were noted for the PAID ($t(316) = -2.624$, $p < .05$) and married ($n = 186$, $M = 0.592$, $SD = 0.154$) compared to not married individuals ($n = 132$, $M = 0.605$, $SD = 0.170$). However, those individuals that responded as married ($n = 186$, $M = 1.875$, $SD = .505$) showed less self-efficacy/empowerment ($t(316) = 2.745$, $p < .05$) than those individual who were not married ($n = 132$, $M = 2.043$, $SD = .579$).

The results shown in Table 2 suggest that the more people living within the participant's household the more distressed people were on the DDS ($r = .104$, $n = 318$, $p < .05$) and the PAID ($r = .145$, $n = 318$, $p < .01$), the less empowerment/efficacy ($r = .047$, $n = 318$, $p < .05$), and the less knowledge they had ($r = -.138$, $n = 318$, $p < .001$). Additionally, education was positively associated with distress on the PAID ($r = .183$, $n = 318$, $p < .01$) and the DDS ($r = .240$, $n = 318$, $p < .01$). However, small, negative associations were found between education and knowledge ($r = -.113$, $n = 318$, $p < .05$) and the self-efficacy/empowerment ($r = -.121$, $n = 318$, $p < .05$).

Employment status was also significantly associated with knowledge ($t(316) = -2.890$, $p < .05$) as participants who reported being unemployed ($n = 144$, $M = .626$, $SD = .177$) showed greater diabetes knowledge than those who were employed ($n = 174$, $M = .574$, $SD = .142$). Similar positive associations were noted between employment and self-efficacy/empowerment ($t(316) = -3.028$, $p < .05$) as unemployed individuals ($n = 144$, $M = .574$, $SD = .177$) showed greater self-efficacy/empowerment than employed individuals ($n = 174$, $M = 1.862$, $SD = .535$). However, employment status was negatively associated with distress as employed individuals (PAID: $n = 174$, $M = 49.53$, $SD = 26.28$; DDS: $n = 174$, $M = 3.391$, $SD = 1.429$) reported higher levels of diabetes distress on the PAID ($t(316) = 6.403$, $p < .05$) and DES ($t(316) = 7.402$, $p < .05$) compared to those who were unemployed on the PAID ($n = 144$, $M = 30.87$, $SD = 25.35$) and DDS ($n = 144$, $M = 2.253$, $SD = 1.282$).

Diabetes Knowledge

The next step in data analysis was to examine the accuracy of knowledge based on the SDKS. As can be seen in Table 4, many participants did not know the correct answer to items on the scale. The items that had the lowest correct answer percentages were related to glycosylated hemoglobin ($n = 231$, 72.6% incorrect), foot care ($n = 213$, 67.0% incorrect), and

testing blood glucose (n = 199, 62.6%). On average, participants had a 55.55% correct (M = .598, SD = .160), and the range of percentages for correct knowledge items was between 21.7% and 92.5%.

In addition, Table 4 also shows participant correct and incorrect response items for the SDKS and their significant associations with diabetes-related distress. For both the DDS and PAID scales, incorrect responses were significantly associated with SDKS items related to glycosylated hemoglobin, testing blood glucose, testing low blood glucose, associated problems, flu, blood glucose levels and clinic appointments. Moreover, correct responses for both the PAID and DDS scales were significantly associated with correct response items on the SDKS related to raised cholesterol, exercise, infection, numbness and tingling, and diabetes complications. When examining the sources of information (See Table 5), individuals most frequently utilized their health care provider/team for their diabetes information. This was followed by diabetes education course(s) and online/website. The least frequently used sources were Social Media and Books/Literature.

Hypothesis 1: There will be a positive association between the accuracy of diabetes-knowledge and the self-efficacy/empowerment of individuals with diabetes.

To determine the association found between the accuracy of diabetes knowledge and self-efficacy/empowerment of individuals with diabetes, a bivariate Pearson's correlation was conducted between the total SDKS score and total DES score. The results show a negative correlation between the accuracy of diabetes knowledge and self-efficacy/empowerment ($r = -.184$, $n = 318$, $p < .01$), contrary to what was expected.

Hypothesis 2: There will be a negative association between the accuracy of diabetes-knowledge and diabetes-related distress.

To determine the association between diabetes knowledge and diabetes-related distress of individuals with diabetes, a bivariate Pearson's correlation was conducted between the total SDKS score, total score for the PAID, and DDS score. The results show negative a correlation between the accuracy of diabetes knowledge and diabetes-related distress as measured by the PAID ($r = -.116$, $n = 318$, $p < .05$) and DDS scales ($r = -.111$, $n = 318$, $p < .05$), as expected (See Table 2).

Hypothesis 3: There will be a negative association between self-efficacy/empowerment and diabetes-related distress.

To determine the association found between the self-efficacy/empowerment and diabetes-related distress of individuals with diabetes, a bivariate Pearson's correlation was conducted between the total DES scores, total scores for the PAID, and DDS scales. The results showed that there was a negative correlation between self-efficacy/empowerment and diabetes-related distress as measured by the PAID ($r = -.016$, $n = 318$, $p < .05$) and DDS scales ($r = -.105$, $n = 318$, $p < .05$), as expected.

Hypothesis 4: Self-efficacy/empowerment will be a mediator of the association between accurate diabetes-knowledge and diabetes-related distress.

As noted above, a mediation was conducted using the procedures outlined by Baron and Kenny (1986) to test the mediating role of empowerment on the association between knowledge and diabetes related distress. There were two separate regression models tested, one for the DDS score and one for the PAID score. For both models, a hierarchical linear regression was utilized where the main effect for knowledge was entered in step one and the effect of empowerment was entered into the model on step two. Results showed that when predicting DDS, knowledge was a significant predictor (See Table 6). Adding in empowerment into the second step added

significantly to the mode fit and empowerment was a significant predictor, but the results did not support the hypothesis that empowerment was a mediator of DDS. Results showed that when predicting PAID, knowledge was a significant predictor (See Table 6). Adding in empowerment into the second step added significantly to the mode fit and empowerment was a significant predictor, but the results did not support the hypothesis that empowerment was a mediator of DDS.

Chapter 4

Discussion

With diabetes being the third most common chronic illness and the seventh leading cause of death in the U.S. (CDC, 2020), it was essential that this study assessed the diabetes knowledge among individuals with T1D and T2D as it relates to their diabetes-related distress. The current literature has suggested that the key to improving diabetes health outcomes is understanding how diabetes knowledge impacts self-efficacy/empowerment in patients with diabetes (Ho et al., 2010). However, although recent technological advances have allowed for an influx in readily available sources of diabetes knowledge, the accuracy of this information can be challenging to both identify and determine. Therefore, this study sought to examine how the accuracy of diabetes knowledge is associated with the self-efficacy/empowerment and diabetes-related distress of individuals with T1D and T2D in data collected from an online sample.

When first looking at sample characteristics and diabetes knowledge, the results of this research provide supporting evidence that diabetes type is associated with knowledge. Although the current study suggests that individuals with T2D have more knowledge, this is inconsistent with work by Fitzgerald et al. (1998) as their research findings show that individual's with T1D have greater knowledge than those with T2D. Additionally, the work by Fitzgerald and colleagues was done nearly 25 years ago; however, this may be that as the visibility and identification of those with T2D increases patients themselves have become more

knowledgeable. This is reasonable to assume as in the current sample the majority reported having T2D.

The results also showed that there were differences in distress based on diabetes type. This finding is consistent with the current literature, where a similar association has been found (Wardian et al., 2018). Patients with T1D often have more reliance on medication regimens, frequently an earlier onset, and modest effects from lifestyle changes alone. It maybe that the extra disease burden from T1D coupled with trying to adjust to a more complex treatment regimen is what is accounting for the increased distress in this group. Wardian and Sun (2014) suggest that possible lack of inclusivity among diabetes self-management strategies and its associated diabetes-related factors may impact an individual's overall belief in their ability to persevere through their diabetes care. Together, these results strongly imply that the type of diabetes that an individual has plays a pivotal role in an individual's knowledge regarding their diabetes diagnosis and coping ability with their diabetes-related distress. Clinically, this may mean that there may not be a "standard" approach to treating everyone with diabetes and type should be considered when developing a treatment plan.

Participant age was positively associated with knowledge and negatively associated with distress. In terms of knowledge, this result is inconsistent with the previous literature suggesting that younger individuals have more knowledge than older individuals (Zowgar et al, 2018). However, for this sample it may alternatively be that older adults have more experience learning about chronic health conditions and searching for information via the internet. In fact, although it was not a variable relevant to the study goals, many individuals in the sample reported additional chronic health conditions (e.g., arthritis [26.1%] and heart disease [14.8%]). These results are consistent, however, with previous studies suggesting older individuals are better able to cope

with distress when compared to younger individuals based on the increase in development of emotion regulation strategies over the adult lifespan (Brummer et al, 2014).

Other demographic results implied significant gender differences between knowledge and distress in which women had higher levels of diabetes knowledge and men had higher levels of distress. Other studies in the literature have also found gender differences in knowledge (Dos Santos et al., 2014) so this finding was not entirely surprising. The findings about distress, however, were surprising as other studies (e.g., Brooks & Roxburgh, 1999) found that women report higher levels of diabetes-related distress than men. It may be that the measures of distress chosen for this study did not account for the general measures of psychological distress, which may elicit different results to that of the current study. Work by Driscoll and colleagues (2018) report that women tend to frequent more perceptions of stigma and bias while navigating the health system. They also highlight the importance of provider communication and sensitivity to the unique needs of women to optimize their care (Driscoll et al., 2018). Collectively, these findings imply a complex association between gender and diabetes-related distress that needs further exploration than the current literature provides. Therefore, future research may help to distinguish these gender differences between general psychological and diabetes-related distress.

There were also significant differences noted in marital status. Results showed that individuals who were married reported more diabetes related distress than those who were not married. In general, this is inconsistent with other studies which have shown that physical and mental health is positively impacted by being in a satisfying dyadic relationship (e.g., Kiecolt-Glaser and Wilson, 2017; Kposowa et al., 2021). It may be that the stressors from diabetes are not as buffered by a satisfying relationship. For instance, couples often share meals and diabetes may lead to more stress around shared eating behavior. When examining more than one's

spouse in each household, however, the results from the current study indicated that as household size increased diabetes related distress increased. Although the current literature is quite limited regarding household size and diabetes more broadly, the results are surprising as previous research has failed to show a correlation between household size and diabetes outcomes (Hempler et al., 2016). Again, this may be related to the types of measures used for distress as the measures selected in the current study attempted to capture a broad picture of psychosocial distress.

The current study showed that individuals who were not married reported more self-efficacy/empowerment than those who were. Work by Kärner Köhler et al. (2018) supports these findings by suggesting that general patient empowerment and self-efficacy are significantly correlated with marital status. It may be that individuals who are married engage in more dyadic coping (Bodenmann et al., 2019) and rely on their partner for support, leading for less of a need to be self-reliant in terms of health care. Similar findings were found in association to household size, where results showed a negative association between the number of people in an individual's household with both self-efficacy/empowerment and knowledge. It may be that although one's relationship partner can provide helpful support; other family members can also help to "pick up the slack" in terms of psychosocial diabetes outcomes. Future research should examine how family/relationship composition is associated to specific types of support or coping efforts to further clarify these ideas.

Finally, education was positively associated with distress, but negatively associated with knowledge and self-efficacy/empowerment. Again, this finding was surprising as Fenwick et al. (2013) found that higher levels of education are positively associated with more knowledge and self-efficacy/empowerment. Alternatively, this study suggests that traditional academic based

education may not equate with health-related knowledge. This is important as it highlights the need to assess patient health literacy and not simply knowing one's education/employment status. Additionally, future research is needed between sociodemographic characteristics, such as age, gender, diabetes type, frequency of BGM, marital status, cohabitation status, education level, and employment status to better understand the variance found within the current study as research on these specific associations were scarce throughout the literature.

Knowledge and Sources

In terms of knowledge, the results of this study found significant variation in the accuracy of correct and incorrect participant responses on the SDKS. Of the correct responses, the present study reported that the top three items with the highest number of correct responses were related to high blood pressure, diabetes diet, and foods low in fat. This is not surprising as these three areas of diabetes care are important in the self-management of diabetes as they're reflective of basic eating behaviors essential to maintaining normal blood sugar levels, a key component to diabetes treatment, and to health-related complications of having diabetes. Of the incorrect responses, the present study reported that the top three items with the lowest correct responses were related to glycosylated hemoglobin, foot care, and testing blood glucose. These results are quite surprising as these three main areas of diabetes care are deemed highly necessary for adequate treatment adherence and the minimization of short-/long-term health complications.

Although this study reported that participants, on the average, got slightly more than half of the knowledge items correct, this was not far off from the number of incorrect responses obtained. Additionally, the main sources of diabetes knowledge were from health care providers, diabetes education courses, and online. The current study results speak to the alarming and monumental discrepancies found in the known diabetes-related information that individuals with

T1D and T2D have impacting their ability to successfully manage their disease. Collectively, these results imply that current knowledge retained by individuals with diabetes is more heavily focused on nutrition and lacking information specific to more relevant treatment areas regarding glycemic control and foot-related diabetes complications.

Hypothesis 1: There will be a positive association between the accuracy of diabetes-knowledge and the self-efficacy/empowerment of individuals with diabetes. Sources of information will be explored as part of this analysis.

To test the first hypothesis, that knowledge will be positively associated with empowerment in individuals with diabetes, the correlation between the SDKS and DES was examined. The results showed as knowledge increased empowerment decreased. These findings are inconsistent with Qiu et al.'s (2020) work that showcases the critical role between knowledge and self-efficacy. The results may be due to the specific measure of knowledge that was used. It may be that the full scope of diabetes related knowledge was not captured, especially given most of the sample had T2D. In fact, there were only a few questions about specific diabetes treatment options and no questions about newer technology associated with blood sugar monitoring. Alternatively, this may be a condition of "information overload" for some individuals where the more that they know the less certain that they feel. This is a topic that has been more heavily researched in patients with cancer (Khaleel et al., 2020), but should be considered for patients with diabetes based on the findings.

Hypothesis 2: There will be a negative association between the accuracy of diabetes-knowledge and diabetes-related distress.

To test the second hypothesis, that knowledge will be negatively associated with diabetes-related, the correlation between the SDKS, PAID, and DDS were examined. To be

expected, examination of this correlation showed the negative association between knowledge and distress. This study result suggests that as an individual's diabetes knowledge increases their levels of distress decrease. Reasons for this association include an individual's sense of understanding and competency in the medical field as it pertains to their ability to manage their diabetes. Patients may feel less distressed when able to decipher health information and find a sense of comfort in knowing that this disease has been studied with known effective treatments and prognosis. Although knowledge was not associated with efficacy and empowerment (see above), an additional variable of confidence in medical system/team should be examined as important in the link between distress and knowledge.

Hypothesis 3: There will be a negative association between self-efficacy/empowerment and diabetes-related distress.

To test the third hypothesis, that there will be a positive association between self-efficacy/empowerment and diabetes-related distress, the correlation between the DES, PAID, and DDS were examined. To be anticipated, examination of this correlation revealed the negative association between self-efficacy/empowerment and diabetes-specific distress. Therefore, these results supported the hypothesis that there was a negative association between self-efficacy/empowerment and distress. Work by Silveira et al. (2019) support this finding as they reported high levels of diabetes-related distress were associated with low levels of self-efficacy/empowerment. Collectively, the literature and current study results imply a moderate association between empowerment and distress. Future research is recommended to further explore and identify these associations.

Hypothesis 4: Self-efficacy/empowerment will be a mediator of the association between accurate diabetes-knowledge and diabetes-related distress.

To test the fourth hypothesis, that self-efficacy/empowerment mediates the association between diabetes-related knowledge and distress, the mediation procedure outlined by Baron and Kenny (1986) was conducted between study variables. Contrary to what was expected, exploration of this potential mediation showed that when predicting distress, knowledge and empowerment were significant predictors. Therefore, these results did not support the hypothesis that empowerment was a mediator of diabetes-related distress. Jiang et al. (2019) supports the mediating relationship that this hypothesis emphasizes by suggesting that self-efficacy plays an important role in the mediation of the association between knowledge and distress on DSM behaviors. However, the current study suggests that they may be other variables that are important to examine (e.g., diabetes type or engagement with treatment team).

Limitations

Several limitations of this study must be noted. To begin, of the 318 participants included with the analysis, only 78 participants had T1D (24.5%) with most diagnoses specific to T2D (n = 240, 75.5%). Although this is representative of the current diabetes population, a larger sample size related to T1D would be beneficial for purposes of best representing the associations between knowledge, self-efficacy, and distress that are specific to diabetes type. For purposes of understanding the role of knowledge, self-efficacy/empowerment, and distress regardless of type, future research is needed to consider the relevant differences between these specifications. Moreover, this would provide a broader understanding when considering the role of knowledge as it relates to all individuals with diabetes and not limit findings to specific populations found within the umbrella of diabetes diagnoses. A second limitation is that the data collected were cross sectional in nature. This limits the type of causal statements that can be made about knowledge, empowerment, and distress. Next, the measures that were chosen for the study were

diabetes based and it may be that use of measures with a more general health orientation of these constructs could help to clarify patterns of association. Additionally, one item was inadvertently left out of a study measure. Although this did not impact the reliability of the measure, it is nonetheless a limitation of the current study. Lastly, as previously mentioned, limitations of this study also included being in an online format as participants were not able to be during their completion of the current study. Moreover, it is unclear if participants sought information from outside sources, such as social media or the internet, when selecting their response items for the SDKS. Therefore, future research must consider using an in-person format to better monitor participants' accuracy to knowledge-related responses.

Strengths and Implications

Despite these limitations, there are several notable strengths of the study. First the study was aimed at examining important psychosocial factors associated with diabetes related distress. Given the biopsychosocial nature of the disease, understating more than lab results in this group becomes critically important. Next, although collected online, the study sample was quite specific in terms of diabetes and the information gleaned from the results is quite informative to diabetes care. Specially the information on knowledge accuracy shows that patients do not know as much as one might expect based on the heavy focus of education and support in both the empirical literature and clinical practice. In addition, the study shows that patients with diabetes are frequently turning to their health care team for care and when coupled with knowledge scores this could mean that additional "booster" sessions or presentation of information in multiple modalities needs to be applied.

Tables

Table 1

Sociodemographic Characteristics of Participants

Characteristics	Full Sample		Characteristics	Full Sample	
	n	%		*n*	%
Criteria			**Education**		
Included	318	38.4%	8th Grade/Less	0	0.0%
Excluded	829	100%	Some High School	8	2.5%
			High School/GED	63	19.8%
Gender			Some College/Technical School	96	30.2%
Male	158	49.7%	Bachelor's	67	21.1%
Female	159	50.0%	Master's	58	18.2%
Non-Binary/Third	1	0.3%	Doctoral	26	8.2%
Marital Status			**Employment**		
Married	186	58.5%	Working Full-Time	147	46.2%
Not Married	132	41.5%	Working Part-Time	27	8.5%
Race/Ethnic Origin			Unemployed Looking for Work	16	5.0%
American Indian/Alaskan Native	9	2.8%	Unemployed Not Looking for Work	5	1.6%
Asian	5	1.6%	Homemaker	17	5.3%
Black/African American	33	10.4%	In School	2	0.6%
Hispanic/Latino	13	4.1%	Retired	65	20.4%
Middle Easter/North African	2	0.6%	Disabled	38	11.9%
Native Hawaiian/Pacific Islander	1	0.3%	Self-Employed	1	0.3%
White	266	83.6%	**Daily Blood Glucose**		
Other	0	0.9%	***Monitoring***		
Housing/Residence			Yes [a]	264	83.0%
Live Alone	53	16.7%	No	54	17.0%
1 Person	75	23.6%	***Frequency/Average*** [a]	4.2	82.4%
2 Person	48	15.1%	***Record Keeping*** [a]		
3 Person	60	18.9%	Yes	204	12.9%
4 Person	62	19.5%	No	41	12.9%
5 or More	20	6.3%	Only Unusual Values	19	6.0%
Comorbidities			**Diabetes Type**		
Arthritis	83	26.1%	Type 1	78	24.5%
Asthma	39	12.3%	Type 2	240	75.5%
Cancer	14	4.4%			
Heart Disease	47	14.8%			
Stroke	15	4.7%			

Note. $N = 318$ ($n = 50$ for each condition). Participants age ranged from were on average 48.8 years old ($SD = 15.6$), and participant age did not differ by condition.

[a] Reflects the number and percentage of participants answering "yes" to this question.

Table 2

Descriptive Statistics and Correlations for Study Variables

Variable	*M*	*SD*	1	2	3	4	5	6	7	8
SDKS	0.60	0.16	—							
DES	1.94	0.54	-.184**	—						
PAID	41.08	27.45	0.116*	0.016*	—					
DDS	2.88	1.48	-.111*	-.105*	.916*	—				
Age	48.8	15.59	.256**	.053	-.394**	-.465**	—			
Housing	3.20	1.551	-.143**	-.153**	-.341**	.391*	-.538**	—		
Education	4.57	1.29	-.113*	-.121*	.183**	.240**	-.190**	-.096*	—	
Duration	2012.22	9.18	-.2*	-.072	.135**	.143**	-.387**	.257**	.224**	—

Note. $^{*}p < .05$. $^{**}p < .01$, (one-tailed).

Table 3

Results of Individual Sample t-Test for Differences in Daily Blood Sugar Monitoring Among Test Variables

Logistic parameter	Test		Don't Test		*t*(316)	*p*	Cohen's
	M	*SD*	*M*	*SD*			*d*
SDKS	.603	.159	.570	.166	-1.410	.080	-.211
DES	1.934	.532	1.995	.594	.742	.229	.111
PAID	42.66	26.876	33.33	29.13	-2.290	.011	-.342
DDS	2.966	1.461	2.436	1.483	-2.424	.008	-.362

Note. Mean parameter values for each of the analyses are shown for those that 'Test' (n = 264) and 'Don't Test' (n = 54), as well as the results of t tests (assuming equal variance) comparing the parameter estimates between the two groups.

Table 4

Correct and Incorrect Items for the Simplified Diabetes Knowledge Scale (SDKS)

Item	Correct		Incorrect		Distress PAID		Distress DDS	
	n	%	n	%	*t*	*p*	*t*	*p*
Diabetes Diet	268	84.3%	50	15.7%	.602	.274	.279	.390
Glycosylated Hemoglobin	87	27.4%	231	72.6%	3.106	.001**	3.539	<.001**
Carbohydrates	213	67%	105	33%	.583	.280	.609	.142
Fat	190	59.7%	128	40.3%	-.293	.385	-.414	.34
Testing Blood Glucose	119	37.4%	199	62.6%	2.946	.002**	3.82	<.001**
Unsweetened Fruit Juice	153	48.1%	165	51.9%	.316	.376	.372	.355
Testing Low Blood Glucose	144	45.3%	174	54.7%	3.688	<.001**	3.406	<.001**
Raised Cholesterol	220	69.2%	98	30.8%	-2.438	.008**	-2.43	.008**
High Blood Pressure	287	90.3%	31	9.7%	-.66	.255	-.652	.257
Exercise	216	67.9%	102	32.1%	2.024	.022*	2.448	.007*
Infection	195	61.3%	123	38.7%	-3.235	<.001**	-3.563	<.001**
Feet	105	33%	213	67%	-.296	.384	-.986	.162
Foods Low in Fat	264	83%	54	17%	.744	.229	.678	.249
Numbness & Tingling	266	52%	52	16.4%	2.43	.008**	2.434	.008**
Associated Problems	149	46.9%	169	53.1%	2.726	.003**	1.724	.043**
Flu	153	48.1%	165	51.9%	-3.822	<.001*	-4.698	<.001*
Blood Glucose Levels[a]	69	21.7%	115	36.2%	2.33	.01**	2.233	.013*
Breakfast & Blood Glucose[a]	102	32.1%	82	25.8%	-.557	.289	-.858	.196
Diabetes Complications	294	92.5%	24	7.5%	1.028	.152	1.969	.025*
Clinic Appointments	139	43.7%	179	56.3%	2.501	.006**	3.132	<.001*

Note. $N = 318$. For purposes of this study, 'Correct' indicates "True" and 'Incorrect' includes "False" and "Don't Know" item responses. Problem Areas in Diabetes (PAID) scale and Diabetes Distress Scale (DDS).

[a] Only completed by insulin-treated participants ($n = 184$, 57.9%).

* $p < .05$, $p < .01$, (one-tailed).

Table 5

Diabetes Knowledge Source Questionnaire (DKSQ)

SDKS Item	Healthcare Provider/Team		Diabetes Education Course(s)		Online/Website		Social Media		Book/Literature	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Diabetes Diet	202	63.5%	147	46.2%	124	39%	66	20.8%	35	11%
Glycosylated Hemoglobin	212	66.7%	122	38.4%	104	32.7%	63	19.8%	33	10.4%
Carbohydrates	127	39.9%	125	39.3%	118	37.1%	60	18.9%	51	16%
Fat	127	39.9%	95	29.9%	102	32.1%	52	16.4%	45	14.2%
Testing Blood Glucose	176	55.3%	123	38.7%	84	26.4%	56	17.6%	30	9.4%
Unsweetened Fruit Juice	141	44.3%	115	36.2%	100	31.4%	55	17.3%	44	13.8%
Testing Low Blood Glucose	153	48.1%	113	35.5%	105	33%	51	16%	38	11.9%
Raised Cholesterol	75	23.6%	64	20.1%	64	20.1%	22	6.9%	18	5.7%
High Blood Pressure	202	63.5%	102	32.1%	106	33.3%	44	13.8%	41	12.9%
Exercise	163	51.3%	109	34.3%	92	28.9%	43	13.5%	34	10.7%
Infection	150	47.2%	95	29.9%	92	28.9%	54	17%	25	7.9%
Feet	112	35.2%	81	25.5%	77	24.2%	50	15.7%	27	8.5%
Foods Low in Fat	179	56.3%	103	32.4%	98	30.8%	48	15.1%	46	14.5%
Numbness & Tingling	192	60.4%	97	30.5%	104	32.7%	47	14.8%	44	13.8%
Associated Problems	119	3.4%	80	25.2%	89	28%	45	14.2%	27	8.5%
Flu	122	38.4%	86	27.0%	79	24.8%	47	14.8%	27	8.5%
Blood Glucose Levels[a]	113	35.5%	77	24.2%	62	19.5%	36	11.3%	28	8.8%
Breakfast & Blood Glucose[a]	102	32.1%	92	28.9%	61	19.2%	37	11.6%	20	6.3%
Diabetes Complications	239	75.2%	127	39.9%	84	26.4%	48	15.1%	44	13.8%
Clinic Appointments	189	59.4%	116	36.5%	91	28.6%	40	12.6%	30	9.4%

Note. $N = 318$ ($n = 50$ for each condition). Participants were on average 39.5 years old ($SD = 10.1$), and participant age did not differ by condition.

[*] Only completed by insulin-treated participants.

Table 6

Hierarchical Linear Regression Analysis for Mediation of Self-Efficacy/Empowerment

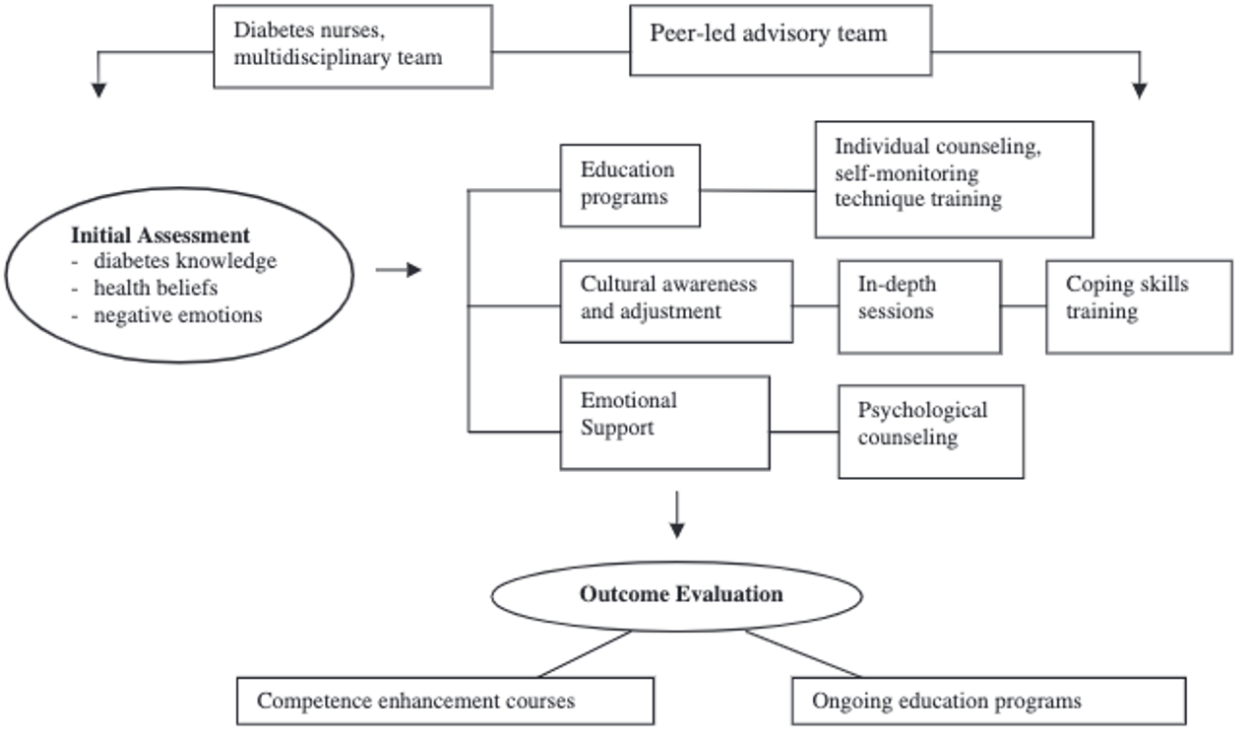
Outcome			B	SEB	Beta	t	F	R2
DDS	Model 1		3.489	.318		10.9651	3.976	.012
		SDKS	-1.025	.514	-.111	-1.994		
	Model 2		4.307	.476			4.660	.029
		SDKS	-1.245	.520	-.135	-2.396		
		DES	-3.54	.154	-.130	-2.300		
PAID	Model 1		52.886	5.915		8.942	4.273	.013
		SDKS	-19.763	9.560	-.116	-2.067		
	Model 2		57.339	8.917		6.431	2.356	.015
		SDKS	-20.957	9.734	-.122	-2.153		
		DES	-1.923	2.880	-.038	-.668		

Note. Diabetes Distress Scale (DDS), Problem Areas in Diabetes (PAID) Scale, Simplified Diabetes Knowledge Scale (SDKS), and Diabetes Empowerment Scale (DES).

Figures

Figure 1

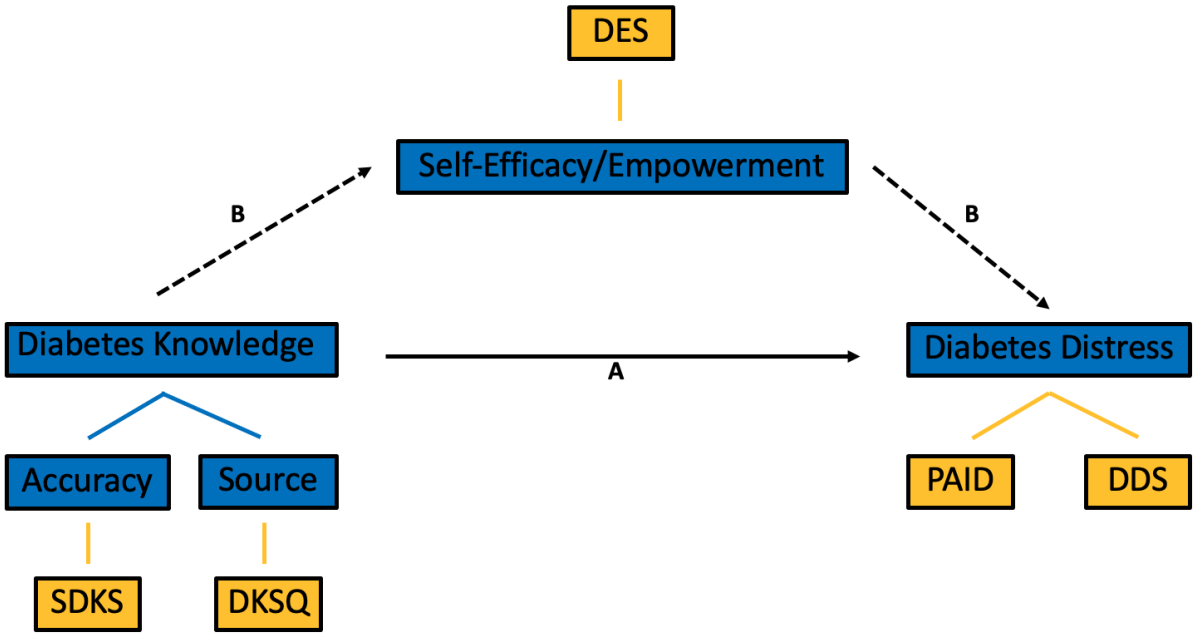
The Diabetes Empowerment Model



Notes. The Diabetes Empowerment Model was adapted from "Diabetes Empowerment Related to Pender's Health Promotion Model: A Metasynthesis," by Ho, Berggren, Dahlborg-Lyckage, Sahlgrenska akademin, Göteborgs universitet, Gothenburg University, Institutionen för vårdvetenskap och hälsa, Institute of Health and Care Sciences, & Sahlgrenska Academy, 2010, *Nursing & Health Sciences, 12*(2), p. 263. Copyright 2010 by the Blackwell Publishing Asia Pty Ltd

Figure 2

Model of Associations Between Test Variables and Constructs



Note. This model represents the assocations explored Diabetes Empowerment Scale (DES), Simplified Diabetes Knowledge Scale (SDKS), Diabetes Knowledge Source Questionnaire (DKSQ), Problem Areas in Diabetes (PAID) Scale, and Diabetes Distress Scale (DDS).

Appendix A: Consent Form

UNIVERSITY OF MICHIGAN CONSENT TO BE PART OF A RESEARCH STUDY

Welcome!

Purpose of the Study: The purpose of this study is to assess the knowledge that people have regarding diabetes self-management and treatment, including their thoughts and emotions about different medical decisions. You will be presented with information on this topic and asked to answer questions about it.

Description of Subject Involvement: The study should take you around 10 minutes to complete. Your participation in this research study is completely voluntary. You have the right to withdraw at any point during the study.

Eligibility Requirements:
- 18 years of age or older
- Read and understand English
- Reside within the United States
- Type 1 or Type 2 Diabetes Diagnosis

Benefits: You may not receive any personal benefits from being in this study. However, others may benefit from the knowledge gained from this study as it may contribute to the research on experiences and knowledge of self-management treatment options among the diabetic population.

Risks and Discomforts: The risks of participating in this study are minimal and do not exceed any risks that occur in everyday life. You may experience discomfort from answering personal questions regarding medical decisions. To alleviate any discomfort all participants will be given a link to psychological resources at the end of the study.

Compensation:
Upon completion of the study, you will receive compensation of $1 via Cloud Research. Payment will be denied if participants are not able to correctly answer a number of questions that demonstrate they were paying attention.

Confidentiality: To protect your information, you will not be asked to identify yourself on the survey. Furthermore, Qualtrics and Cloud Research will remove your IP address from your data file, so that your identity remains anonymous. Data from this study may be stored and used for future research. The data will have no identifiable information. Therefore, you will not be notified of the data used in future research.

Voluntary Nature of the Study: Participating in this study is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time.

Contact Information:

Please contact the researchers listed below to:
• Obtain more information about the study
• Ask a question about the study procedures
• Express a concern about the study

Principal Investigator: Celia Bourgeau, B.A.
Email: cbourgea@umich.edu

Faculty Advisor: Dr. Michelle Leonard
Email: mtleon@umich.edu

If you have questions about your rights as a research participant, or wish to obtain information, ask questions or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board (IRB-HSBS)
2800 Plymouth Road Building 520, Room 1169
Ann Arbor, MI 48109-2800
Telephone: 734-936-0933 or toll free 866-936-0933
Fax: 734-936-1852
E-mail: irbhsbs@umich.edu

You can also contact the University of Michigan Compliance Hotline at 1-866-990-0111

This study (HUM00208280) has been determined to be exempt from IRB oversight by the Health Sciences and Behavioral Sciences Institutional Review Board.

By clicking the button below, you acknowledge that your participation in the study is voluntary, you meet all the eligibility requirements above, and that you are aware that you may choose to terminate your participation in the study at any time and for any reason.

- ○ I Agree (1)
- ○ I Disagree (2)

Appendix B: Demographics Questionnaire

I am at least 18 years or older.

- ○ Yes (1)
- ○ No (2)

I am ____ years old.

I am able to read and understand English.

- ○ Yes (1)
- ○ No (2)

I currently live in the United States of America (USA).

- ○ Yes (1)
- ○ No (2)

I am currently diagnosed with... (Please select all that apply)

- ☐ Heart Disease (1)
- ☐ Asthma (2)
- ☐ Cancer (3)
- ☐ Type 1/Type 2 Diabetes (4)
- ☐ Stroke (5)
- ☐ Arthritis (6)
- ☐ None of the Above (7)

Based on your previous responses, you selected "Type 1/Type 2 Diabetes". Please specify your current diabetes diagnosis type.

- ○ Type 1 Diabetes (1)
- ○ Type 2 Diabetes (2)

What year were you first told you had diabetes?

Sex:

- ○ Male (1)
- ○ Female (2)
- ○ Non-binary / third gender (3)
- ○ Prefer not to say (4)

What is your marital status?

- ○ Never Married (1)
- ○ Separated (2)
- ○ Divorced (3)
- ○ Widowed (4)
- ○ Married (5)

What is your ethnic origin/race? (Please select all that apply)

- ☐ American Indian or Alaska Native (3)
- ☐ Asian (4)
- ☐ Black or African American (2)
- ☐ Hispanic or Latino (8)
- ☐ Middle Eastern or North African (6)
- ☐ Native Hawaiian or Other Pacific Islander (5)
- ☐ White (1)
- ☐ Other (7)

How many people live with you?

- ○ I live alone (1)
- ○ 1 person (2)
- ○ 2 people (3)
- ○ 3 people (4)
- ○ 4 people (5)
- ○ 5 or more (6)

How much schooling have you had? (Years of formal schooling completed)

- ○ 8 grades or less (1)
- ○ Some high school (2)
- ○ High school graduate or GED (3)
- ○ Some college or technical school (4)
- ○ Bachelor's Degree (5)
- ○ Master's Degree (6)
- ○ Doctoral Degree (7)

Which of the following best describes your current employment status?

- ○ Working full-time, 35 hours or more a week (1)
- ○ Working part-time, less than 35 hours a week (2)
- ○ Unemployed or laid off and looking for work (3)
- ○ Unemployed and not looking for work (4)
- ○ Homemaker (5)
- ○ In school (6)
- ○ Retired (7)
- ○ Disabled, not able to work (8)
- ○ Something else? (Please specify) (9)

Do you test your blood sugar?

- ○ No (1)
- ○ Yes (2)

On an average day that you test, how many times per day do you test your blood sugar?

Do you keep a record of your blood sugar test results? (Check one box)

- ○ No (1)
- ○ Yes (2)
- ○ Only Unusual Values (3)

Appendix C: Simplified Diabetes Knowledge Scale

Now you will be asked to answer true/false questions about diabetes-related knowledge. After each statement, please select the appropriate response of "True", "False", or "Don't Know". Once you've selected your answer, you will then be asked how you know this information from the available response options and select all that apply.

The diabetes diet is a healthy diet for most people.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Glycosylated hemoglobin (HbA1c) is a test that measures your average blood glucose level in the past week.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

A pound of chicken has more carbohydrates in it than a pound of potatoes.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Orange juice has more fat in it than low fat milk.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Urine testing and blood testing are both equally as good for testing the level of blood glucose.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Unsweetened fruit juice raises blood glucose levels.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

A can of diet soft drink can be used for treating low blood glucose levels.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Using olive oil in cooking can help prevent raised cholesterol in the blood.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Exercising regularly can help reduce high blood pressure.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

For a person in good control, exercising has no effect on blood sugar levels.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Infection is likely to cause an increase in blood sugar levels.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Wearing shoes a size bigger than usual helps prevent foot ulcers.

- ○ True (1)

- ○ False (2)
- ○ Don't Know (3)

Eating foods lower in fat decreases your risk for heart disease.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Numbness and tingling may be symptoms of nerve disease.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Lung problems are usually associated with having diabetes.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

When you are sick with the flu you should test for glucose more often.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Do you take insulin as part of your treatment plan?

- ○ Yes (1)
- ○ No (2)

High blood glucose levels may be caused by too much insulin.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

If you take your morning insulin but skip breakfast your blood glucose level will usually decrease.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Having regular check-ups with your doctor can help spot the early signs of diabetes complications.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Attending your diabetes appointments stops you from getting diabetes complications.

- ○ True (1)
- ○ False (2)
- ○ Don't Know (3)

Appendix D: Diabetes Knowledge Source Questionnaire

How do you recall obtaining information related to this question? (Please select all that apply)

- ☐ Health Care Provider/Team (1)
- ☐ Diabetes Education Course(s) (3)
- ☐ Online/Website (4)
- ☐ Social Media (5)
- ☐ Book/Literature (6)
- ☐ Other: (7)

Appendix E: Diabetes Empowerment Scale

In general, I believe that I:

	Strongly Agree (1)	Agree (2)	Neutral (3)	Disagree (4)	Strongly Disagree (5)
...know what part(s) of taking care of my diabetes that I am satisfied with. (1)	○	○	○	○	○
...know what part(s) of taking care of my diabetes that I am dissatisfied with. (2)	○	○	○	○	○
...know what part(s) of taking care of my diabetes that I am ready to change. (3)	○	○	○	○	○
...know what part(s) of taking care of my diabetes that I am not ready to change. (4)	○	○	○	○	○
...can choose realistic diabetes goals. (5)	○	○	○	○	○
...know which of my diabetes goals are most important to me. (6)	○	○	○	○	○
...know the things about myself that either help or prevent me from reaching my diabetes goals. (7)	○	○	○	○	○
...can come up with good ideas to help me reach my goals. (8)	○	○	○	○	○

...am able to turn my diabetes goals into a workable plan. (9)	○	○	○	○	○
...can reach my diabetes goals once I make up my mind. (10)	○	○	○	○	○
...know which barriers make reaching my diabetes goals more difficult. (11)	○	○	○	○	○
...can think of different ways to overcome barriers to my diabetes goals. (12)	○	○	○	○	○
...can try out different ways of overcoming barriers to my diabetes goals. (13)	○	○	○	○	○
...am able to decide which way of overcoming barriers to my diabetes goals works best for me. (14)	○	○	○	○	○
...can tell how I'm feeling about having diabetes. (15)	○	○	○	○	○
...can tell how I'm feeling about caring for my diabetes. (16)	○	○	○	○	○
...know the ways that having diabetes causes	○	○	○	○	○

stress in my life. (17)					
...know the positive ways I cope with diabetes-related stress. (18)	○	○	○	○	○
...know the negative ways I cope with diabetes-related stress. (19)	○	○	○	○	○
...can cope well with diabetes-related stress. (20)	○	○	○	○	○
...know where I can get support for having and caring for my diabetes. (21)	○	○	○	○	○
...can ask for support for having and caring for my diabetes when I need it. (22)	○	○	○	○	○
...can support myself in dealing with my diabetes. (23)	○	○	○	○	○
...can motivate myself to care for my diabetes. (24)	○	○	○	○	○
...know enough about diabetes to make self-care choices that are right for me. (25)	○	○	○	○	○
...know enough about myself as a person to make diabetes care choices that	○	○	○	○	○

are right for me. (26)					
...am able to figure out if it is worth my while to change how I take care of my diabetes. (27)	○	○	○	○	○

Appendix F: Problem Areas in Diabetes Scale

Which of the following diabetes issues are currently a problem for you? On a scale from 0 to 4, with 0 indicating "Not a Problem" and 4 indicating "A Serious Problem, please select the best response for you and provide an answer for each question.

	0 - Not a Problem (1)	1 - A Slight Problem (2)	2 - A Moderate Problem (3)	3 - Somewhat Serious Problem (4)	4 - A Serious Problem (5)	5 - A Very Serious Problem (6)
Feeling that my doctor doesn't know enough about diabetes and diabetes care. (1)	○	○	○	○	○	○
Feeling that diabetes is taking up too much of my mental and physical energy every day. (2)	○	○	○	○	○	○
Not feeling confident in my day-to-day ability to manage diabetes. (3)	○	○	○	○	○	○
Feeling angry, scared and/or depressed when I think about living with diabetes. (4)	○	○	○	○	○	○
Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes. (5)	○	○	○	○	○	○
Feeling that I am not testing my blood sugars frequently enough. (6)	○	○	○	○	○	○

Feeling that I will end up with serious long-term complications, no matter what I do. (7)	○	○	○	○	○	○
Feeling that I am often failing with my diabetes routine. (8)	○	○	○	○	○	○
Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods). (9)	○	○	○	○	○	○
Feeling that diabetes controls my life. (10)	○	○	○	○	○	○
Feeling that my doctor doesn't take my concerns seriously enough. (11)	○	○	○	○	○	○
Feeling that I am not sticking closely enough to a good meal plan. (12)	○	○	○	○	○	○
Feeling that friends or family don't appreciate how difficult living with diabetes can be. (13)	○	○	○	○	○	○
Feeling overwhelmed by the demands of living with diabetes. (14)	○	○	○	○	○	○

Feeling that I don't have a doctor who I can see regularly enough about my diabetes. (15)	○	○	○	○	○	○
Not feeling motivated to keep up my diabetes self management. (16)	○	○	○	○	○	○
Feeling that friends or family don't give me the emotional support that I would like. (17)	○	○	○	○	○	○
Feeling constantly concerned about food and eating? (18)	○	○	○	○	○	
Worrying about the future and the possibility of serious complications? (19)	○	○	○	○	○	
Feelings of guilt or anxiety when you get off track with your diabetes management? (20)	○	○	○	○	○	
Not “accepting” your diabetes? (21)	○	○	○	○	○	
Feeling unsatisfied with your diabetes physician? (22)	○	○	○	○	○	
Feeling that diabetes is taking up too much of your mental and physical energy every day? (23)	○	○	○	○	○	

Feeling alone with your diabetes? (24)	○	○	○	○	○
Feeling that your friends and family are not supportive of your diabetes management efforts? (25)	○	○	○	○	○
Coping with complications of diabetes? (26)	○	○	○	○	○
Feeling “burned out” by the constant effort needed to manage diabetes? (27)	○	○	○	○	○

Appendix G: Diabetes Distress Scale

Listed below are 17 potential problem areas that people with diabetes may experience. On a scale from 0 to 5, with 0 indicating "Not a Problem" and 5 indicating "A Very Serious Problem", during the past month how have each of these items distressed or bothered you?

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would select "Not a Problem". If it is very bothersome to you, you might select "A Very Serious Problem".

	0 - Not a Problem (1)	1 - A Slight Problem (2)	2 - A Moderate Problem (3)	3 - Somewhat Serious Problem (4)	4 - A Serious Problem (5)	5 - A Very Serious Problem (6)
Feeling that my doctor doesn't know enough about diabetes and diabetes care. (1)	○	○	○	○	○	○
Feeling that diabetes is taking up too much of my mental and physical energy every day. (2)	○	○	○	○	○	○
Not feeling confident in my day-to-day ability to manage diabetes. (3)	○	○	○	○	○	○
Feeling angry, scared and/or depressed when I think about living with diabetes. (4)	○	○	○	○	○	○

Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes. (5)	○	○	○	○	○	○
Feeling that I am not testing my blood sugars frequently enough. (6)	○	○	○	○	○	○
Feeling that I will end up with serious long-term complications, no matter what I do. (7)	○	○	○	○	○	○
Feeling that I am often failing with my diabetes routine. (8)	○	○	○	○	○	○
Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods). (9)	○	○	○	○	○	○

Feeling that diabetes controls my life. (10)	○	○	○	○	○	○
Feeling that my doctor doesn't take my concerns seriously enough. (11)	○	○	○	○	○	○
Feeling that I am not sticking closely enough to a good meal plan. (12)	○	○	○	○	○	○
Feeling that friends or family don't appreciate how difficult living with diabetes can be. (13)	○	○	○	○	○	○
Feeling overwhelmed by the demands of living with diabetes. (14)	○	○	○	○	○	○
Feeling that I don't have a doctor who I can see regularly enough about my diabetes. (15)	○	○	○	○	○	○
Not feeling motivated to keep up my	○	○	○	○	○	○

diabetes self management. (16)						
Feeling that friends or family don't give me the emotional support that I would like. (17)	○	○	○	○	○	○

Appendix H: Debriefing Form

Without individuals like yourself, advances in health care may not be made.

Thank you for your interest or participation in the Knowledge Empowers research study. We hope that by exploring how access and accuracy of knowledge can strengthen the sense of empowerment individuals with Type 1 and Type 2 Diabetes have to help them stay healthy and happy. This sheet is provided as a reminder that should your participation in this project lead to a desire to seek additional services, you may contact any of the agencies listed below.

Psychological Services US National Suicide Prevention Lifeline
Call 1-800-273-TALK (8255); En Español 1-888-628-9454
Crisis Text Line: Text "HELLO" to 741741

Substance Use Services
SAMHSA National Helpline
Confidential free help, from public health agencies, to find substance use treatment and information.
1-800-662-4357

Please select the following link to complete this survey:
COMPLETE THIS SURVEY

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