# THESIS

# TYPE II DIABETES MELLITUS SELF-MANAGEMENT: RELATING DIABETES DISTRESS, SOCIAL SUPPORT, SELF-EFFICACY, AND PERFORMANCE OF DIABETES SELF-CARE ACTIVITIES

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In partial fulfillment of the requirements

For the Degree of Master of Science

Colorado State University

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Spring 2020

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#### ABSTRACT

# TYPE II DIABETES MELLITUS SELF-MANAGEMENT: RELATING DIABETES DISTRESS, SOCIAL SUPPORT, SELF-EFFICACY, AND PERFORMANCE OF DIABETES SELF-CARE ACTIVITIES

Type 2 Diabetes Mellitus (T2DM) is a widespread chronic disease that negatively impacts an individual's health and well-being, particularly when uncontrolled. Due to the nature of T2DM, individuals are responsible for the challenge of self-managing the disease. Several factors act as barriers and facilitators to self-management, but the literature has failed to establish consensus about how these factors interact with one another. The present study utilized a correlational design to examine the relationships among diabetes distress, social support, self-efficacy, and performance of diabetes self-care activities. A total of 33 adults with T2DM participated in the study by completing a battery of surveys regarding performance of diabetes self-care activities and psychosocial factors. Self-efficacy was associated with diabetes distress ( $\rho = -.419$ ). Support satisfaction was related to both self-efficacy ( $\rho = .495$ ) and diabetes distress ( $\rho = -.431$ ), although relationships were not found with other aspects of social support. We did not find any significant relationships among the psychosocial variables and performance of diabetes self-care activities, though both psychosocial factors and performance of diabetes self-care activities were linked to key health indicators like A1C and BMI. Our findings suggest that these psychosocial factors should be areas of interest for healthcare practitioners, researchers, and individuals with T2DM. Diabetes distress, self-efficacy, and social support should be assessed and monitored, in addition to performance of diabetes self-care activities. Future research should continue to explore

relationships among psychosocial and contextual factors and their potential impact on ability to successfully self-manage T2DM.

#### ACKNOWLEDGEMENTS

First, I would like to express my gratitude to my advisor, Dr. Matthew Malcolm for his guidance, support, and patience throughout this process. I sincerely thank you for encouraging me to truly take ownership of my thesis and for giving me the freedom to design and execute my own study. I appreciate all the support you provided me along the way from navigating an IRB amendment to statistical analysis, and everything in between.

I would also like to thank my committee members, Dr. Karen Atler and Dr. Jennifer Portz. In particular, I would like to thank Dr. Karen Atler for helping me improve my academic writing skills and critical thinking abilities not only through her role on my committee, but also as my professor. Thank you to Dr. Anne Williford for providing support, even on short notice. And to Dr. Jennifer Portz for your support and insight during the beginnings of this project.

Next, I would like to thank the Department of Occupational Therapy for providing Wanda Mayberry Research Funding, which allowed me to incentivize participation in the study. I also wish to recognize my professors and peers, who always challenged me to think critically and in novel ways.

Finally, I would like to thank all of my family and friends who provided endless support and encouragement throughout this journey. To my family, thank you for always believing in me. To Erin Miramontes, thank you for helping me stay balanced. To the Raskins, thank you for your pep talks and for helping me gain insight into the experience of living with a chronic condition. Finally, to Dorothy Kalmbach, Justine Cawthorne, Meghan Dunnigan, and Sydney Pelster, thank you for being the absolute best support system I could ask for, during graduate school and beyond.

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#### **CHAPTER 1 INTRODUCTION**

#### Background

Type II Diabetes Mellitus (T2DM) is a chronic disease affecting approximately 30 million individuals in the United States, or 9.4% of the population (Centers for Disease Control and Prevention [CDC], 2017). When uncontrolled, T2DM can lead to multiple adverse health complications, including cardiovascular disease, diabetic retinopathy, diabetic neuropathy, and diabetic nephropathy (World Health Organization [WHO], 2016). Diabetes self-management (DSM) is key to prevent the progression of the disease, however individuals struggle to consistently perform diabetes self-care activities (WHO, 2016). Research demonstrates that adherence is related to a multitude of interpersonal and contextual factors (Ahola & Groop, 2013), however the complexity of these interactions warrants further study. Failing to better understand why individuals struggle with DSM prevents provision of appropriate interventions to address those factors (Nagelkerk et al., 2006). This means that individuals will experience continued disease progression, ultimately resulting in a host of unfavorable health and lifestyle outcomes (WHO, 2016).

In addition to negative health outcomes, T2DM can negatively impact the ability to participate in desired and meaningful daily activities. Studies suggest a significant link between diabetes and functional disability (Gregg et al., 2002; Marinho et al., 2016). Individuals with T2DM have reported problems with mobility, self-care, and domestic life (Marinho et al., 2016). Additionally, complications of diabetes such as vision impairment and neuropathy can negatively impact performance of home management tasks, driving, and community mobility (Estes, 2016).

T2DM can also complicate common tasks like self-care by introducing a host of new activities like blood glucose monitoring, foot care, and medication management (Estes, 2016).

Because of T2DM's nature as a lifelong chronic disease, individuals with T2DM are primarily responsible for T2DM management. In order to promote successful T2DM selfmanagement, healthcare associations recommend attending DSM classes and participating in preventive care practices (CDC, 2017; American Diabetes Association [ADA], 2018a). In support of this recommendation, approximately 4,100 DSM education and support programs exist in the United States. However, despite the availability of these support programs, only 54.4% of adults with diagnosed diabetes reported attending a self-management class after diagnosis (CDC, 2017). The CDC (2017) also reported that only 63% of diabetic adults perform daily glucose monitoring, while another examination of DSM activities found that only 52% of individuals with T2DM follow a diet and 26% follow an exercise regimen (Shultz et al., 2001). Although decreased attendance of self-management classes offers one explanation for decreased adherence in DSM, exploration of other factors influencing DSM is needed.

Psychosocial factors have been implicated as one such group of significant and influential factors impacting DSM (Gonzalez et al., 2016). Psychological factors like self-discipline, locus of control, coping and stress management skills, and self-efficacy may be barriers to successful and consistent performance of diabetes self-care activities (Ahola & Groop, 2013; Aljasem et al., 2001; Brown et al., 2002; Gazmararian et al., 2009; Nagelkerk et al., 2006). Social relationships have also been identified as a potential barrier to one's ability to fulfill complex self-management requirements (Wiebe et al., 2016). The present study's aim was to expand upon our current knowledge regarding psychosocial factors by focusing on three specific psychosocial factors – diabetes distress, social support, and self-efficacy. The literature suggests that these

three constructs are relevant to DSM, but studies have seldom examined them in conjunction with one another and have failed to establish consensus regarding their impact.

We examined correlational relationships among diabetes distress, social support, selfefficacy, and performance of diabetes self-care activities. Gaining a better understanding of these relationships is beneficial to guide future research in this area and to help healthcare practitioners better understand barriers preventing their patients from successfully self-managing.

#### **Literature Review**

#### **T2DM Self-Management**

DSM is required to maintain optimal blood glucose levels and reduce the risk of secondary complications, with the ultimate goal of improving both longevity and quality of life (Ahola & Groop, 2013). DSM requires significant time and involves nearly all aspects of an individual's life (Nagelkerk et al., 2006). To be successful, individuals need to integrate DSM into their lifestyle by modifying established routines and habits to include recommended diabetes self-care activities (Fritz, 2014).

The American Association of Diabetes Educators (AADE) identified and published a summary of seven self-care behaviors deemed "essential for successful and effective diabetes self-management" (Tomky et al., 2008, p. 445). These behaviors—known as the AADE7<sup>TM</sup> – consist of the following: healthy eating, being active, monitoring, taking medication, problem solving, healthy coping, and reducing risks. This framework is meant to provide guidelines for DSM education and provide standardized nomenclature to facilitate better communication among healthcare providers to improve coordination of care (Tomky et al., 2008).

The AADE7<sup>™</sup> is not the only set of guidelines available to inform practitioners. The ADA annually publishes "Standards of Medical Care in Diabetes," an extensive document

delineating the current best practices in diabetes care. Within this document, the ADA states that "ongoing patient self-management education and support are critical" (ADA, 2018a, p. S1) and advocates for the provision of Diabetes Self-Management Education and Support (DSMES) services as part of a comprehensive plan of care. The ADA recommends that DSM education be provided "at diagnosis, annually, when complicating factors arise, and when transitions in care occur" (ADA, 2018b, p. S38). DSMES services are also recommended by the AADE and the Academy of Nutrition and Dietetics, with the goal of supporting individuals' ability to make decisions regarding their own healthcare and to effectively self-manage T2DM (Powers et al., 2015).

Despite the promotion of DSM guidelines, negative outcomes persist and T2DM continues to be the 7<sup>th</sup> leading cause of death in the United States (CDC, 2017). These outcomes imply a disconnect between our knowledge about DSM and an individual's ability to implement that knowledge in daily life. A significant portion of the research on DSM has focused on identifying interpersonal, intrapersonal, and large scale contextual factors that may be barriers to successful T2DM management. However, we still do not fully understand the relationships among those factors or whether they are predictive of performance of diabetes self-care activities. This issue is not unique to T2DM. Bos-Touwen et al. (2015) examined multiple factors contributing to patient activation for self-management among four chronic health conditions, including T2DM. However, they were only able to explain 16% of the variance between levels of activation. Similarly, a study seeking to identify predictors of self-care for patients with chronic heart failure was only able to explain about 10% of the variance in self-care (Rockwell & Riegel, 2001). These results support the need for further exploration of barriers and predictive factors impacting DSM.

#### Stress

The relationship between stress and health has been researched extensively, revealing a complex but well-established relationship between chronic, excessive stress and negative effects on overall health that contribute to the development of chronic disease (Acabchuk et al., 2017; Hart, 2009). Although we understand how stress can be a risk factor for development of disease, we know less about how stress plays a role post-diagnosis. The literature suggests that there are multiple avenues by which stress can impact diabetes health outcomes. One key understanding that has emerged is that stress and diabetes appear to have a reciprocal relationship. That is, stress impairs the ability to self-manage, while difficulty with self-management can result in increased stress (Nomura et al., 2000). Stress can be detrimental to DSM through both physiological pathways and through disruption of life roles or ability to perform necessary diabetes self-care activities (Cox & Gonder-Frederick, 1992). The present study was specifically interested in this proposed relationship between stress and performance of diabetes self-care activities. However, we examined this relationship from a disease-specific lens by specifically measuring diabetes distress.

**Diabetes distress.** Diabetes distress has been defined as "a range of negative emotional responses...to aspects of living with and managing diabetes balanced against an appraisal of available coping resources" (Dennick et al., 2017, p. 899). Gonzalez et al. (2011) further specified that emotional reactions may be in response to "the diagnosis of diabetes, threat of complications, self-management demands, unresponsive providers, and/or unsupportive interpersonal relationships" (p. 236).

The construct of diabetes distress emerged as researchers began to question whether a diagnosis of depression accurately represented the unique psychosocial complications of having diabetes. Diabetes distress is related to depressive symptoms (Fisher et al., 2007; Schmitt et al., 2015), however multiple studies have been able to distinguish between the two, specifically by examining their relationship to outcomes such as glycemic control (Aikens, 2012; Fisher et al., 2010; Schmitt et al., 2015). Diabetes distress is correlated with glycemic control (Aikens, 2012; Fisher et al., 2010; Schmitt et al., 2010) whereas no significant correlations were found between depression and A1C (Fisher et al., 2010), suggesting that diabetes distress has its own unique role to play independent of depressive symptoms.

In terms of T2DM, most inquiries have focused on the transaction between diabetes distress and glycemic control with less focus on performance of diabetes self-care activities (Jannoo et al., 2017; Lee et al., 2018). However, some research has found that diabetes distress is predictive of medication adherence (Aikens, 2012; Jannoo et al., 2017). If diabetes distress is associated with poor medication adherence, it is likely that it is also associated with other diabetes self-care activities. The present study sought to close this gap by looking at diabetes to the growing body of research on the potential role of social support as a mediating factor between distress and DSM (Baek et al., 2014; Lee et al. 2018). Current research in this area has also primarily focused on glycemic control, as opposed to performance of diabetes self-care activities.

## **Social Support**

Social support plays a significant role in chronic disease management, including DSM (Chen et al., 2018; Gomes et al., 2017; Koetsenruijter et al., 2016; Rotberg et al., 2016). Social

support is defined as the perception that assistance is available (Ahola & Groop, 2013). The word "perception" is key as some researchers have suggested that an individual's perceived social support is more important than the actual support received (Sherbourne & Stewart, 1991). Social support may be categorized as structural or functional. Structural refers to the quantifiable aspects of a network, while functional encompasses the qualitative dimensions of social support (Schiøtz et al., 2012). Functional support can be broken down into subcategories of support including emotional, tangible, and informational (Ahola & Groop, 2013; Chen et al., 2018; Koetsenruijter et al., 2016).

Because T2DM impacts nearly every aspect of an individual's daily life (Nagelkerk et al., 2006), an individual's social network will inevitably become involved in their disease. Furthermore, many of the lifestyle changes that individuals with T2DM are required to make involve activities that occur in a social context, like eating, exercising, and healthy coping (Rotberg et al., 2016). Therefore, social supports may be called upon to provide emotional support or assistance with tasks like healthy eating and exercise. The social network may also become involved by providing assistance with seeking out information and resources (Koetsenruijter et al., 2016; Newton-John et al., 2017).

Social networks will vary in size and include multiple sources like family, friends, spouse, community, and healthcare providers. The literature suggests that size and source of support matter (Ahola & Groop, 2013; Gomes et al., 2017; Koetsenruijter et al., 2016; Rotberg et al., 2016; Shaw et al., 2006). For instance, Koetsenruijter et al. (2016) suggest that the size of the social network is of particular importance for those who have a limited education, with larger support networks positively influencing performance of diabetes self-care activities. Because individuals with less than a high school education are at a higher risk for developing T2DM

(CDC, 2017), this relationship is notable. Some evidence implies that familial (Ahola & Groop, 2013; Gomes et al., 2017) and spousal (Henry et al., 2013) support are particularly important to successful DSM while others emphasize the benefit of interacting with other individuals who share a T2DM diagnosis (Rotberg et al., 2016). In an assessment of performance of diabetes self-care activities, Shaw et al. (2006) found that family and friends were particularly helpful for maintaining diet and performing foot care whereas community resources played a larger role in monitoring and exercise.

Shaw et al.'s (2006) study implies that social support can influence performance of diabetes self-care activities. Significant associations have been found between social support and healthy eating (Bouldin et al., 2017; Rosland et al., 2014; Schiøtz et al., 2012; Shaw et al., 2006), physical activity (Nicklett et al., 2013; Rosland et al., 2014), and medication adherence (Nicklett et al., 2013; Osborn & Egede, 2012). However, the literature lacks consensus about some of these relationships. Other studies failed to find a significant relationship between social support and physical activity (Bouldin et al., 2017; Schiøtz et al., 2012) and between social support and medication adherence (Rosland et al., 2014; Schiøtz et al., 2012). Similar discrepancies exist regarding the influence of social support on foot care (Nicklett et al., 2013; Rosland et al., 2014; Schiøtz et al., 2014; Schiøtz et al., 2013; Rosland et al., 2014). One meta-analysis suggested a correlation between social support and monitoring (Song et al., 2017), but this claim requires further research.

Although some studies have demonstrated little or no relationship between social support and DSM (Chlebowy & Garvin, 2006; Gleeson-Kreig et al., 2002), most of the research that is currently available illustrates a relationship between the two. However, the nature of this relationship is unclear as the literature demonstrates conflicting results. Identification of this

discrepancy indicates that further research is required to better understand the transaction occurring between social support and DSM.

Additionally, little research has focused on satisfaction with social support despite implications that it is an important consideration for performance of diabetes self-care activities. Tang et al. (2008) reported that satisfaction was predictive of monitoring. Gleeson-Kreig et al. (2002) found high levels of dissatisfaction with the amount of social support received for performance of diabetes self-care activities. The present study examined not only type and quantity of support, but also considered an individual's satisfaction with perceived support.

Despite conflicting results regarding the relationship between social support and DSM, there is consensus that DSM interventions should target social support (Nicklett et al., 2013; Zhang et al., 2007). Evidence suggests that interventions targeting social support have been successful in improving outcomes (Banbury et al., 2017; McEwen et al., 2010; Spencer-Bonilla et al., 2017). Gaining a better understanding of social support's role in DSM will contribute to our understanding of why individuals struggle to integrate and will allow practitioners to design effective social support interventions.

# Self-Efficacy

Broadly, self-efficacy may be defined as "an individual's perception of his/her own ability to perform a specific task in a given situation" (Krichbaum et al., 2003, p. 657). As it pertains to DSM, self-efficacy is the belief in one's ability to "exercise control over one's health habits" (Bandura, 2004, p. 144). Self-efficacy is also a primary component of Social Cognitive Theory (SCT), which serves as the theoretical basis for this study and will be discussed in a later section.

Self-efficacy has been identified in the literature as a key facilitator, or potential barrier, to DSM. Because the individual with T2DM is typically the principal provider of care, it is imperative that they feel confident in their ability to successfully complete tasks associated with the complex challenge of DSM. One review even suggests that low self-efficacy is one of the "strongest and most consistent barriers to effective self-management" (Krichbaum et al., 2003, p. 658). However, the certainty of this statement should not negate the complicated nature of the relationship between self-efficacy and DSM. Schunk and Usher (2012) explain that self-efficacy has positive effects on motivation, learning, achievement, and self-regulation but caution that self-efficacy can be incredibly fragile, as failing to cope with, and solve, problems associated with T2DM complications can lead to a decline in self-efficacy. Conversely, successfully navigating problems has the potential to increase self-efficacy.

A substantial amount of research has been conducted regarding the relationship between self-efficacy and DSM. There is a general consensus in the literature that self-efficacy directly impacts DSM, with multiple authors concluding that self-efficacy is a strong predictor of performance of diabetes self-care activities (Devarajooh & Chinna, 2017; Jiang et al., 2019; Schinckus et al., 2018; Walker et al., 2015). Research has also established a positive relationship between self-efficacy and glycemic control (Cherrington et al., 2010; D'Souza et al., 2017; Gao et al., 2013). Furthermore, self-efficacy's effect on DSM has been investigated in conjunction with other common influential factors like social support (Lee et al., 2019; Mladenovic et al., 2014; Peimani et al., 2018), health literacy (Sarkar et al., 2006; Schinckus et al., 2018), and psychosocial factors. Associations between self-efficacy and performance of diabetes self-care activities have been documented, but these findings are less prevalent in the literature than examinations of outcomes like glycemic control. Researchers have found correlations between

self-efficacy and exercise (Allen, 2004; Heiss & Petosa, 2016; Sarkar et al., 2006), diet and blood glucose monitoring (Mishali et al., 2011; Sarkar et al., 2006), and foot care (Sarkar et al., 2006).

Self-efficacy may also be impacted by certain demographic factors. D'Souza et al. (2017) reports a positive association between age and duration of diabetes and level of self-efficacy. Cherrington et al. (2010) suggest differences between genders, finding significant relationships among self-efficacy, depression, and glycemic control for men but not women.

Although the relationship between self-efficacy and DSM is well-established, further research is needed to examine how self-efficacy influences performance of diabetes self-care activities (Mishali et al., 2011). The present study worked to close this gap by utilizing measures that allowed for exploration of these more specific relationships. Additionally, while multiple studies have examined self-efficacy in relation to social support, diabetes distress, and performance of diabetes self-care activities, there is a lack of research examining all factors simultaneously.

#### **Theoretical Framework**

Social Cognitive Theory (SCT) is a multifaceted theory of behavior that seeks to explain how individuals acquire and maintain behaviors within a social context (Bandura, 1998). More specifically, its goal is to "explain how people change their behavior through self-control and reinforcement in order to start goal-directed behavior which can be maintained over time" (Thojampa & Sarnkhaowkhom, 2019, p. 1251). The question of how individuals maintain goaldirected behavior is largely what researchers are concerned with when trying to understand DSM. As a result, research has frequently tested the utility of SCT for explaining or predicting performance of diabetes self-care activities in order to further support and encourage SCT's use

in developing interventions (Allen, 2004; Plotnikoff et al., 2008; Thojampa & Sarnkhaowkhom, 2019).

SCT revolves around the key concept of reciprocal determinism, which posits that personal, behavioral, and social or environmental factors are constantly and dynamically interacting with one another to facilitate or impede a given behavior (Schunk & Usher, 2012). The variables of interest in the present study can be sorted into each of these three categories: self-efficacy and diabetes distress are personal factors, performance of diabetes self-care activities is the behavioral factor, and social support is the environmental factor.

SCT was selected as the theoretical framework to guide the present study as its central concept aligns with, and supports, this study's fundamental interest in how various constructs interact with one another within the context of DSM. In conjunction with a thorough review of the literature, SCT provides a well-researched, theoretical basis to inform and support the study hypotheses.

#### **Purpose of the Study**

As demonstrated in the existing literature, receiving a diagnosis of T2DM requires a significant lifestyle adjustment. Multiple psychosocial factors have been presented as barriers and facilitators of that adjustment, but the relationship between DSM and critical psychosocial factors is not well-established. Identifying how such factors relate may reveal unknown barriers to DSM. Gaining more information will move us toward solving the larger problem of why individuals struggle to integrate despite our knowledge about how to successfully manage this disease. Without a better understanding of why individuals struggle to integrate DSM into their daily routines, it is likely that we will see the current negative healthcare trends associated with T2DM (CDC, 2017) continue. We posited that diabetes distress, social support, and self-efficacy

were especially important factors to examine. Although research has previously demonstrated connections between these constructs and DSM, the existing literature lacks consensus and fails to adequately consider interactions occurring among all constructs simultaneously.

The purpose of this study was to examine relationships among diabetes distress, social support, self-efficacy, and performance of diabetes self-care activities. This research project was an extension of the Taking On Diabetes to Advance You (TODAY) Project, which examined the experiences and challenges of managing T2DM with a focus on individuals with low socioeconomic status.

#### **Statement of the Research Question**

To address these gaps, this study answered the following research question: What are the relationships between diabetes distress, social support, self-efficacy, and performance of diabetes self-care activities in adults diagnosed with T2DM?

We hypothesized that we would find the following significant correlations between the four variables of interest: (1) Increased levels of diabetes distress will be associated with decreased levels of social support, (2) Increased self-efficacy will be associated with decreased diabetes distress, (3) Increased social support will be associated with increased self-efficacy, and (4) Increased social support, increased self-efficacy, and decreased diabetes distress will be associated with increased performance of diabetes self-care activities.

#### **CHAPTER 2 METHODS**

#### Methods

The study employed a correlational design to explore the relationships between diabetes distress, social support, self-efficacy, and performance of diabetes self-care activities. The study included a combination of objective and subjective self-report measures to ascertain the relationships between the variables of interest. Each measure is summarized in Table 1.

#### Recruitment

The study utilized a convenience sample of adults with T2DM. Participants were recruited using a combination of flyers and online postings to diabetes-specific forums. When required, permission was obtained from forum moderators. Flyers and forum postings provided basic information about the study, including the inclusion criteria. Inclusion criteria were: (1) adults aged 18 and above, (2) diagnosed with T2DM, and (3) able to read and write English. Individuals who determined that they met inclusion criteria and were interested in participating in the study were directed to a survey link. Prior to starting the survey, participants were required to read and agree to a consent form. The study procedures were approved by the Institutional Review Board of Colorado State University and all participants provided informed consent.

To incentivize participants, they were offered a chance to win an iPad. At the end of the survey, participants were asked if they would like to be entered into a raffle to win an iPad. If participants indicated "yes," Qualtrics sent them to a second survey where they were able to provide their contact information. This information was not in any way linked to their responses. If participants indicated "no," they received the standard end of survey message.

#### **Procedures and Measures**

The battery of paper-based assessments was manually converted into an electronic format and delivered via Qualtrics, an online survey platform. The Qualtrics survey was formatted to prevent individuals from taking the survey multiple times, although they were able to stop and resume the survey if they were unable to complete it in one sitting. The time required to complete the survey was approximately 15 minutes. Participants were required to provide an answer to each question before moving on, thus preventing skipped responses.

Raw data were downloaded to an Excel spreadsheet and visually inspected for missing or incomplete responses. Missing and non-numerical data on cholesterol and blood pressure were removed from the spreadsheet before statistical analysis. Participants' scores for each measure were calculated within the spreadsheet, following scoring directions. When applicable, subscale scores were calculated within the spreadsheet as well.

**Demographics.** All participants completed a modified version of the Health History and Demographics Questionnaire, which was developed as part of the TODAY project. The questionnaire gathered information on the following: gender, age, ethnicity, race, employment status, income level, cholesterol, and blood pressure. Height and weight were collected in order to calculate body mass index (BMI). Participants also reported their A1C, a measure of an individual's average blood glucose over a 3-month period (ADA, 2020). Participants were also asked if they have ever attended diabetes education sessions.

**Diabetes self-care activities.** Data on participants' performance of diabetes self-care activities was obtained by administering the Summary of Diabetes Self-Care Activities (SDSCA) (Appendix A). The SDSCA was originally developed in 1994 but was revised in 2000 following a review of studies utilizing the SDSCA. The "specific diet" subscale was removed as it was

found to be unreliable. The revised version includes questions that reflect current practices in DSM like carbohydrate counting and reducing the risk of cardiovascular disease (Toobert et al., 2000).

The SDSCA is a self-report measure requiring individuals with T2DM to answer questions about performance of diabetes self-care activities over the past week. The measure examines the following domains: diet, exercise, blood sugar testing, foot care, smoking, and medication management. These categories are reflective of several AADE7<sup>™</sup> self-care behaviors, including healthy eating, being active, monitoring, taking medication, and reducing risks. A total score is obtained by calculating the mean of all responses. Subscale scores are obtained by calculating the mean of responses within each subscale. Possible scores range from 0 to 7 days.

Although not all-encompassing, the SDSCA was chosen for this study because it is a widely used and accepted measure of performance of diabetes self-care activities. The SDSCA has been compared to other diabetes self-care measures to determine concurrent validity, resulting in high correlations for exercise and modest correlations for diet and monitoring (Weinger et al., 2005). Additionally, the SDSCA has good internal consistency with average inter-item correlations of r = 0.47 (Toobert et al., 2000).

**Diabetes distress.** The Diabetes Distress Scale (DDS) (Appendix B) is a 17-item selfreport measure created to assess psychosocial distress related to diabetes. The measure may be broken down into four separate subscales: emotional burden (EB), physician-related distress (PD), regimen-related distress (RD), and diabetes-related interpersonal distress (ID). Participants read each statement and utilize a Likert scale to indicate how problematic that particular domain has been over the past month. Responses range from 1 to 6, where 1 = not a problem and 6 = a

very serious problem (Jannoo et al., 2017; Lee et al., 2018). A total score is obtained by calculating the mean of all responses. Subscale scores are obtained by finding the mean of the responses to the component items of that scale. This process yields a mean item score ranging from 1 to 6. Mean items score of 3 or higher indicates a moderate level of distress and warrants further clinical attention. The DDS has good internal consistency overall ( $\alpha = 0.93$ ) and for each subscale ( $\alpha_{EB} = 0.88$ ,  $\alpha_{PD} = 0.88$ ,  $\alpha_{RD} = 0.90$ ,  $\alpha_{ID} = 0.88$ ). It also has strong validity with higher overall scores being "associated with being younger and more depressed, using insulin, poorer self-care, and having elevated lipid levels" (Polonsky et al., 2005, p. 629).

Social support. Because of the complexity of social support, research suggests that administering more than one social support measure is preferred in studies examining the effects of social support (Al-Dwaikat & Hall, 2017). Multiple aspects of social support can be measured; the present study included measures of functional support, structural support, and satisfaction with support. The Medical Outcomes Study Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991) is a self-administered 19-item measure designed to measure functional social support. Since its development, the MOS-SSS has been modified to reduce the number of items and alter the subscales that are measured (Priede et al., 2018). For the purposes of this study, the modified Medical Outcomes Study Social Support Survey (mMOS-SSS) (Appendix C) was used to decrease time burden on participants. The mMOS-SSS is an 8-item self-administered measure that includes the first 8 items of the MOS-SSS, covering instrumental and emotional support subscales. Although it was initially created for use with women with breast cancer (Ganz et al., 2003), it has since been evaluated for use in primary care and with more diverse populations (Gómez-Campelo et al., 2014; Togari & Yokoyama, 2016). Similar to the original measure, participants rate how often someone in their network would be available to assist them with each

item. Participants provide a rating on a 5-point Likert scale, where from 1 = none of the time and 5 = all of the time. A total raw score is obtained by summing all of the responses. Instrumental support subscale scores are determined by summing the first four items, while emotional support subscale scores are determined by the last four items. The raw scores will be converted to a 0-100 scaled score, with higher scores indicating stronger social support. Neither the authors of the original measure, nor the authors of the modified version offer defined cut-offs for interpretation of scores. However, utilizing the published means obtained during the development of the original measure is suggested (RAND Corporation, 2019; Sherbourne & Stewart, 1991).

Studies examining the psychometric properties of the mMOS-SSS have found good internal reliability ( $\alpha = 0.91$ ) and construct and discriminant validity (Gómez-Campelo et al., 2014; Moser et al., 2012; Priede et al., 2018). Its psychometric properties are comparable to the original measure (Moser et al., 2012; Priede et al., 2018). Additionally, a study examining the factor structure of the original measure and two abbreviated versions concluded that the mMOS-SSS is the most efficient of all versions (Priede et al., 2018).

The Social Support Questionnaire Short Form (SSQ6) (Sarason et al., 1987) (Appendix D) is a self-administered 6-item survey that measures perceived structural social support and satisfaction (Al-Dwaikat & Hall, 2017). Participants rate each item on 2 dimensions – number of perceived supports and satisfaction. For each statement, participants list how many individuals in their network they perceive would support them ranging from 0 to 9 persons. Then, they rate their satisfaction with that support on a 6-point Likert scale, where 1 = very dissatisfied and 6 = very satisfied. Scoring is performed by determining the mean number of person-supports and mean satisfaction. Possible mean person-supports scores range from 0 to 9, and possible mean satisfaction scores range from 1 to 6.

The SSQ6 is a derivative of the Social Support Questionnaire (SSQ) (Sarason et al., 1983), developed to ease the time burden on participants. While the SSQ was initially developed for college students, it has been used for individuals with T2DM (Chlebowy & Garvin, 2006). Few studies have examined the psychometric properties of the SSQ6, but existing literature suggests good reliability and validity (Al-Dwaikat & Hall, 2017; Sarason et al., 1987). When compared to a battery of other social support measures, correlation coefficients were similar between the SSQ and the SSQ6 suggesting that the abbreviated version is representative of the original measure (Sarason et al., 1987).

Self-efficacy. The Diabetes Empowerment Scale – Short Form (DES-SF) (Appendix E) is a measure of diabetes-related psychosocial self-efficacy. The DES-SF is an 8-item measure derived from the full 28-item scale in order to ease time burden on participants (Anderson et al., 2003). The abbreviated measure has good reliability ( $\alpha = 0.84$ ) and content validity.

The DES-SF asks participants to indicate their level of agreement with statements regarding their attitudes toward their diabetes. Participants respond on a 5-point Likert scale, where 1 = strongly disagree and 5 = strongly agree. Some sample statements include "I believe that I can try out different ways of overcoming barriers" or "I believe that I know enough about myself as a person to make diabetes care choices that are right for me." (Anderson et al., 2003). Scoring is completed by finding the mean of all responses. Possible mean scores range from 1 to 5, with higher scores indicating higher diabetes-related self-efficacy.

#### **Statistical Analysis**

Statistical analysis was completed using SPSS software. A Spearman's correlation was run to analyze the relationships between all of the domains being measured. Correlations of  $r_s = 0.25$  to 0.49 were considered to be weak,  $r_s = 0.50$  to 0.74 to be moderate, and  $r_s = 0.75$  and

above to be strong (Portney & Watkins, 2009). Uncorrected significance was set at p = 0.05. However, because the total number of correlations is 120, setting the significance level to p = 0.05 means that about 6 correlations would be significant by chance. To address this issue of multiple comparisons, the Bonferroni correction was used to adjust the significance level to p = 0.001. The following results section will report correlations at both p = 0.05 and p = 0.001.

#### **CHAPTER 3 RESULTS**

#### Results

Of the 44 individuals who received the survey, 33 (75%) completed it. The average age was 53.8 years (SD, 12.0; range, 34-79). The average A1C was 6.34 (SD, 1.0; range, 4.8 - 8.7), with 23 (70%) participants reporting an A1C below the recommended level of 7.0. The average BMI was 32.8 (SD, 10.7; range, 16.0 - 70.6), with 13 (39%) participants in the overweight range (25.0 - 29.9) and 15 (45%) participants in the obese range (30.0+). Of the sample, 22 (67%) participants indicated they were employed. About half the sample (n=16) indicated they had previously attended a diabetes education session. Further details about demographic variables are summarized in Table 2. All correlations are represented in Table 3. The following sections describe findings for each measure incorporated into the survey.

#### **Diabetes Self-Care Activities**

On the SDSCA, participants reported performance of diabetes self-care activities an average of 4 of the past 7 days (mean, 4.2 days, SD, 1.0; range, 1.9 - 6.6). Mean subscale scores are represented in Figure 1. Blood glucose monitoring was the most frequently performed activity (mean, 5.6 days, SD, 2.3; range, 0 - 7), followed by foot care (mean, 4.2 days, SD, 1.5; range, 1.4 - 7.0). The least frequent activities were exercise (mean, 3.8 days, SD, 2.4; range, 0 - 7) and adherence to a diet plan (mean, 3.5 days, SD, 1.3; range, 0.8 - 6.4). Total SDSCA scores were moderately correlated with cholesterol, although only 18 (55%) out of 33 participants reported usable data on cholesterol. For those 18 participants, increased performance of self-care activities was moderately associated with decreased cholesterol levels. We also found moderately strong correlations between cholesterol and exercise, with more frequent exercise

linked to lower cholesterol. Lower cholesterol was also moderately associated with more frequent foot care. SDSCA scores were weakly associated with BMI and A1C; increased performance of diabetes self-care activities was linked to lower BMI and lower A1C. A1C was weakly correlated with diet and moderately correlated with exercise, signifying that more frequent adherence to diet and exercise recommendations was associated with lower A1C. Similarly, BMI was weakly correlated with diet indicating that participants who more frequently followed dietary recommendations had lower BMI. SDSCA subscale correlations are represented in Table 4. When correcting for multiple comparisons (p = .001), none of the correlations remained statistically significant.

## **Diabetes Distress**

The mean item score across all participants was 2.1 (SD, 1.0; range, 1.0 - 5.4) indicating that, on average, the participants were experiencing minimal levels of distress. However, some participants met or exceeded a mean score of 3, indicating that they were experiencing moderate levels of distress. Of the 33 participants, 4 (12%) scored a 3 or above on the total scale, 6 (18%) scored a 3 or above on the emotional burden subscale, 7 (21%) scored a 3 or above on the physician-related subscale, 8 (24%) scored a 3 or above on the regimen-related subscale, and 7 (21%) scored a 3 or above on the diabetes-related interpersonal subscale. Subscale and total scores are represented in Figure 2.

Diabetes distress was weakly correlated with age; younger participants tended to have higher levels of distress. Increased levels of diabetes distress were moderately associated with increased A1C. DDS scores were weakly correlated with BMI, with higher levels of distress associated with higher BMI. We found moderate associations between A1C and emotional burden and between A1C and physician-related distress, indicating that higher levels of

emotional burden and physician-related distress were associated with increased A1C. Additionally, A1C was strongly correlated with regimen-related distress indicating that higher levels of regimen-related distress was also associated with increased A1C (Figure 3). Age was weakly associated with emotional burden and physician-related distress, and moderately associated with diabetes-related interpersonal distress; younger participants reported higher levels of distress on all three of these subscales. DDS subscale correlations are represented in Table 5.

When correcting for multiple comparisons (p = .001), the moderate correlation between diabetes distress and A1C remained statistically significant. Moderate to strong correlations between A1C and diabetes distress subscales – emotional burden, physician-related distress, and regimen-related distress – also remained statistically significant.

## **Social Support**

The mean number of persons available to provide support was 2.9 persons (SD, 2.2; range, 0 - 9). Mean satisfaction with available support was 4.6 (SD, 1.4; range: 1 - 6), indicating that, on average, participants were slightly satisfied with the amount of support they have. Mean number of person-supports and mean satisfaction ratings were weakly correlated with each other; as the number of person-supports increased, satisfaction ratings increased as well. Mean number of person-supports was moderately associated with BMI, with more person-supports associated with decreased BMI. Mean satisfaction ratings were weakly correlated with systolic blood pressure and age. On average, younger participants reported lower levels of satisfaction. Mean satisfaction scores were weakly correlated with DDS scores; increased satisfaction ratings were associated to be a satisfaction rating score as a substant of support score as a substant of person-support score as a substant of person-support score as a substant of support score as a substant of person-support score as a substant of

higher levels of diabetes-related self-efficacy, as evidenced by the moderate correlation between mean satisfaction scores and DES-SF scores.

The mean scale score on the mMOS-SSS was 55 (SD, 26.4; range, 9 - 100). On the instrumental support subscale, the mean scale score was 54 (SD, 32.7; range, 0 - 100), and on the emotional support subscale, the mean scale score was 56 (SD, 25.6; range, 13 - 100). Each of these mean scores indicate that participants reported below average availability of social support. Mean scores on the total measure were weakly correlated with income; higher income was associated with increased availability of social support. mMOS-SSS scores were also weakly correlated with the mean number of person-supports, signifying a positive relationship between perceived number of supports and perceived availability of support. A moderately strong relationship was also found between mMOS-SSS scores and mean satisfaction ratings, with an increase in perceived availability of support associated with higher satisfaction ratings.

When correcting for multiple comparisons (p = .001), only the moderate relationships between mean number of person-supports and BMI and between satisfaction and mMOS-SSS scores remained statistically significant.

# Self-Efficacy

The mean score was 4.0 (SD, 0.9; range, 1.5 - 5.0), indicating average levels of diabetesrelated self-efficacy overall. Scores on the DES-SF were weakly associated with age and A1C. Participants with higher self-efficacy tended to be older and have lower A1C. DES-SF scores were weakly associated with total DDS scores, indicating that higher diabetes-related selfefficacy was related to decreased distress. We also found relationships between DES-SF scores and two DDS subscales: emotional burden and regimen-related distress. Higher diabetes-related self-efficacy was moderately associated with a decrease in emotional burden and weakly

associated with a decrease in regimen-related distress. When correcting for multiple comparisons (p = .001), only the moderate relationship between diabetes-related self-efficacy and emotional burden remained statistically significant.

#### CHAPTER 4 DISCUSSION AND CONCLUSION

#### Discussion

This study assessed the relationships among diabetes distress, social support, diabetesrelated self-efficacy, and performance of diabetes self-care activities in a sample of 33 adults with T2DM. We found significant relationships between distress, self-efficacy, and social support, but none of these variables were significantly correlated with performance of diabetes self-care activities. However, diabetes distress, self-efficacy, and social support do appear to be related to outcomes of performance of diabetes self-care activities in some capacity, as evidenced by their relationships with health indicators like A1C and BMI.

Age emerged as a relevant demographic factor, especially regarding distress levels, selfefficacy, and satisfaction with social support. Younger individuals reported higher levels of distress, especially emotional burden and physician-related distress. The feelings of fear and helplessness associated with emotional burden may be particularly prevalent in younger individuals with shorter disease duration (Kasteleyn et al., 2015). Younger individuals may have less experience with physicians and may feel less secure in their relationship with their healthcare team (Hessler et al., 2011). The most significant source of distress for younger participants was interpersonal distress. Younger individuals also reported lower support satisfaction. Together these findings suggest that age plays a role in how individuals perceive the support they receive from family or friends. A possible explanation is that quality of support improves over time, or that individuals need less support as they gain experience living with the disease. Similar to D'Souza et al. (2017), we found a positive relationship between age and selfefficacy suggesting that individuals become more self-efficacious as they get older. This result is

likely linked to number of years spent managing the disease, although we did not collect data on date of diagnosis.

Diabetes distress was associated with satisfaction but not other aspects of support, providing partial support for Hypothesis 1. Social support has long been considered a potential buffer against stress (Cohen & Wills, 1985), so our failure to find more correlation among distress and social support is unexpected. Decreased distress was related to increased support satisfaction highlighting the importance of individual assessments of support quality based on personal preferences and needs. Newton-John et al. (2017) previously demonstrated that individuals assess and respond differently to support; for instance, some view non-involvement as positive and desirable while others view it in a negative light. While Tang et al. (2008) similarly discovered an inverse relationship between satisfaction and diabetes distress, they did not utilize a formal measure of satisfaction with social support. By utilizing a formal measure of satisfaction, we were able to build upon and provide additional evidence to support Tang et al.'s (2008) initial conclusions regarding satisfaction and diabetes distress. Baek et al. (2014) also found a relationship between satisfaction and diabetes distress; however, unlike the present study, Baek et al. (2014) also found that the size of support network was associated with diabetes distress, and further posited that social support may be a protective factor against diabetes distress.

Increased self-efficacy was linked to lower diabetes distress, supporting Hypothesis 2. Self-efficacy specifically shared relationships with regimen-related distress and emotional burden, suggesting that higher self-efficacy is associated with feeling less overwhelmed, helpless, or incompetent in one's ability to perform their DSM routine. In support of the relationship between these variables, SCT suggests that feeling less stressed while performing a

task can help people feel more self-efficacious (Schunk & Usher, 2012). Both Jiang et al. (2019) and Devarajooh and Chinna (2017) found a similar relationship between self-efficacy and diabetes distress. Our study examined diabetes-related self-efficacy more globally, while Jiang et al. (2019) and Devarajooh and Chinna (2017) each measured self-efficacy as it relates to specific diabetes self-care activities like diet and exercise. Therefore, our findings build upon prior research by highlighting the importance of a global sense of self-efficacy as it relates to diabetes distress.

Higher self-efficacy was associated with increased satisfaction with social support, in partial support of Hypothesis 3. Similar to our findings regarding distress and support, satisfaction was the only support domain significantly linked to self-efficacy. Social support intervention studies have generated evidence of a meaningful relationship between social support and self-efficacy. Peimani et al. (2018) found that peer support improved self-efficacy, while participants in Mladenovic et al. (2014) intervention reported a decline in exercise self-efficacy once participation in a support group ceased. However, neither of these studies considered satisfaction as a relevant domain of support. Though research has examined the impact of social support on feelings of efficacy, support satisfaction has not been a common area of focus. Lack of data about support satisfaction is likely due in large part to utilization of multiple social support measures, many of which do not consider satisfaction. We utilized general measures of social support alongside a diabetes-specific self-efficacy measure, which may explain why our results did not exhibit a correlation between overall support and efficacy.

Lee et al. (2019) did examine satisfaction with support in conjunction with self-efficacy, but only within the context of autonomy support from an informal health supporter. Lee et al. (2019) reported that autonomy support and respect for the supporter were associated with self-

efficacy but, contrary to our findings, did not find a relationship between satisfaction and selfefficacy. Future research regarding support and efficacy may need to take a more targeted approach by using diabetes-specific measures. Currently, there is a lack of diabetes-specific social support measures for use with adults with T2DM (Al-Dwaikat & Hall, 2017). The Diabetes Social Support Questionnaire – Family Version (La Greca & Bearman, 2002) and the Diabetes Social Support Questionnaire – Friends Version (Bearman & La Greca, 2002) have been developed for use with adolescents with Type 1 Diabetes Mellitus. Future measure development may benefit from taking a similar approach of focusing on one source of support at a time like family, friends, or peers.

Contrary to the existing body of literature, we did not find a significant relationship between performance of diabetes self-care activities and self-efficacy, diabetes distress, or social support. This lack of significant findings may be due to measure selection or small sample size. However, we did find relationships between all four variables of interest and select health indicators. Performance of diabetes self-care activities was significantly associated with A1C, BMI, and cholesterol, confirming the expectation that consistent and adequate performance of diabetes self-care activities results in favorable health outcomes. In accordance with the literature, increased self-efficacy (Cherrington et al., 2010; D'Souza et al., 2017; Gao et al., 2013) and decreased diabetes distress (Aikens, 2012; Fisher et al., 2010) were associated with lower A1C, indicating some relationship between these two factors and successful management. A1C was specifically related to emotional burden, physician-related distress, and regimen-related distress, suggesting that those who feel a sense of control over diabetes, have positive patientprovider relationships, and feel confident in their performance of diabetes self-care activities may be better equipped to meet glycemic targets. Such characteristics better equip these

individuals to take responsibility for their own care and overcome frequently cited barriers to self-management like emotional challenges, provider factors, and low self-efficacy (Ahola & Groop, 2013). Although we were unable to draw connections between diabetes distress and performance of diabetes self-care activities, our findings relating diabetes distress to A1C reaffirm the importance of managing diabetes distress to achieve and maintain glycemic control. Social support was not linked to A1C but was associated with BMI, another important health indicator that has been linked with increased risk of complications from T2DM (Gray et al., 2015). Participants with larger social networks tended to have lower BMI. Diet and exercise adherence are two components of achieving and maintaining a healthy BMI. Therefore, our finding regarding support and BMI suggests that there may a relationship between social support and diet and exercise adherence that was not captured in our results.

Failing to obtain support for Hypothesis 4 is an unexpected result. The lack of correlation between performance of diabetes self-care activities and psychosocial variables, in conjunction with findings relating both performance of diabetes self-care activities and psychosocial variables to glycemic control and BMI, raises questions about the utility of our diabetes self-care measure and its ability to accurately capture an individual's ability to self-manage. Even though the SDSCA is a valid and reliable measure of performance of diabetes self-care activities, the present findings suggest that it has its limitations. Although this measure encompasses many diabetes self-care activities, it fails to measure problem-solving and healthy coping, two critical self-care behaviors outlined within the AADE7<sup>TM</sup> (Tomky et al., 2008). Furthermore, it is not sensitive to individualized recommendations that study participants may be following per their healthcare team. For example, some may need to check their blood sugar multiple times a day while others may not need to adhere to a similar frequency (Association of Diabetes Care &
Education Specialists [ADCES], 2020). The SDSCA attempts to consider such individual differences by including the question, "on how many of the last seven days did you test your blood sugar the number of times recommended by your health care provider?" (Toobert et al., 2000); however, the overall mean score will still be affected by responses about blood sugar testing regardless of attempts to acknowledge the nuances in self-care. Researchers continue to explore both the utility and the limitations of the SDSCA (Caro-Bautista et al., 2014; Lu et al., 2016; Schmitt et al., 2016). Some research has begun highlighting the need for further psychometric testing on the revised measure (Lu et al., 2016), while other research emerges to suggest that an alternative diabetes self-care measure may be superior (Schmitt et al., 2016).

# **Future Directions**

The results of this study contribute to the larger body of literature seeking to understand how contextual and psychosocial factors interact with one another as both facilitators and barriers to successful performance of diabetes self-care activities. Conflicting and unexpected findings confirm the need for additional research. However, our findings in conjunction with prior research can be used to support development of targeted interventions to help people become more successful with DSM.

Additional research is needed among minority groups, including non-English speaking communities and those living in rural areas. Research will benefit from further efforts to develop and establish standardized sets of diabetes-specific measures. The current body of literature contains a multitude of measures for every variable of interest, making it difficult to compare results. Future research should also work toward establishing causality between variables. In particular research should focus on variables strongly correlated with one another, like A1C and diabetes distress.

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## Limitations

The present study has several limitations. One significant limitation was a small sample size. Furthermore, the sample lacked diversity in certain areas. The sample was not racially or ethnically diverse and the majority of participants (70%) reported well-controlled A1C. The sample also represented higher income brackets, with a median income between \$70,000-\$89,999 and 45% of participants reporting an income above \$90,000. We did not collect data on education level, disease duration, or diabetes severity, which limited our picture of the sample.

Measures were only provided in English, precluding non-English speakers from participating in the study. The battery of surveys was delivered solely online, so individuals without access to the Internet or individuals who are not proficient in using the Internet may have been unable to participate. Because surveys were delivered online, the researcher also did not have the ability to clarify questions for participants or provide additional guidance. Data on cholesterol and blood pressure was incomplete due to a lack of more direct instruction on how to report this information. This problem may have been remediated by restricting non-numerical survey responses for these items. An additional limitation was the amount of correlations that were no longer statistically significant at the more conservative p-value. Including fewer variables or a larger sample size to provide more data or inclusion of fewer variables may have resulted in more significant findings.

Although most of our measures were diabetes-specific, the study may have benefited from a diabetes-specific social support measure in order to better test hypotheses surrounding social support. While our self-efficacy measure was diabetes-specific, it focused on global feelings of efficacy and empowerment in terms of coping with and managing diabetes as opposed to being focused on specific self-management behaviors. A different measure of self-

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efficacy may have allowed us to better assess its relationship to performance of diabetes self-care activities. Unexpected results also raise questions about the utility of our diabetes self-care measure. Difficulty selecting appropriate measures is not unique to our study. DSM research as a whole lacks standardization of measures, which is likely a significant contributor to differing results.

# Conclusion

This study found relationships among three psychosocial factors associated with DSM but was not able to establish a direct connection between those factors and performance of diabetes self-care activities. Our findings contribute to a growing body of literature seeking to understand how psychosocial and contextual variables facilitate or inhibit successful integration of DSM into a daily routine.

Our findings contain several implications for healthcare practitioners developing effective interventions for individuals working to self-manage this chronic condition. Findings surrounding diabetes distress suggest a need for increased focus on stress management. Additionally, our results suggest that the source of stress changes over time, indicating that practitioners may need to focus on targeting more specific stressors depending on factors like age. Given its relationship to distress and A1C, self-efficacy should continue to be an area of focus for healthcare practitioners. Practitioners must be sensitive to the fragility of self-efficacy and frequently reassess patients' feelings of efficacy. Our findings imply that practitioners should pay closer attention to patients' satisfaction with their support network. When addressing social support, practitioners must take a patient-centered approach that focuses on establishing support that maximizes an individual patient's satisfaction instead of assuming that a certain type of social support will be most effective. Future research should continue to examine the

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dynamics among factors impacting DSM in order to gain additional understanding, establish consensus, and provide guidance for DSM intervention.

# TABLES AND FIGURES

# Table 1

List of Measures

Measure	Domains/Subscales	Units	Time Frame
Summary of Diabetes Self-Care Activities (SDSCA)	<ol> <li>Diet</li> <li>Exercise</li> <li>Blood sugar testing</li> <li>Foot care</li> <li>Smoking</li> <li>Medication management</li> </ol>	Number of days	7 days
Diabetes Distress Scale (DDS)	<ul> <li>Diabetes distress</li> <li>Subscales:</li> <li>1. Emotional burden</li> <li>2. Physician-related</li> <li>3. Regimen-related</li> <li>4. Diabetes-related Interpersonal</li> </ul>	Likert scale 1 to 6 1 = not a problem 6 = a very serious problem	1 month
Modified Medical Outcomes Study Social Support Survey (mMOS-SSS)	Social support Subscales: 1. Instrumental 2. Emotional	Likert scale 1 to 5 1 = none of the time 5 = all of the time	None
Social Support Questionnaire Short Form (SSQ6)	<ul><li>Social support</li><li>Subscales:</li><li>1. Number of supports</li><li>2. Satisfaction</li></ul>	0 to 9 supports Likert scale 1 to 6 1 = very dissatisfied 6= very satisfied	None
Diabetes Empowerment Scale – Short Form (DES-SF)	Diabetes-related self-efficacy	Likert scale 1 to 5 1 = strongly disagree 5 = strongly agree	None

# Table 2

Demographics	
Factor	n
Gender (n=33)	
Female	18
Male	15
Age (n=33)	
18-34	1
35-54	18
55-74	13
75+	1
A1C (n=33)	
<7.0	23
>7.0	10
BMI (n=33)	
<18.5 (underweight)	1
18.5-24.9 (normal)	4
25.0-29.9 (overweight)	13
30.0+ (obese)	15
Cholesterol (n=18)	
<140	8
140-200	6
200-240	2
240+	2
Systolic blood pressure (n=30)	
100-120	9
120-140	21
Diastolic blood pressure (n=30)	
45-70	6
70-95	24
Ethnicity (n=33)	
Hispanic or Latino	0
Non-Hispanic or Latino	33
Race (n=33)	
White	31
Asian	1
Other	1
Diabetes education (n=33)	
Yes	16
No	17
Employment status (n=33)	
Yes	22
No	11
Income (n=33)	
<\$10,000	2
\$10,000-\$29,999	3
\$30,000-\$49,999	4
\$50,000-\$69,999	5
\$70,000-\$89,999	4
\$90,000-\$149,999	10
>\$150,000	5

### Table 3

	<i>n</i>	r	15
Spearman	Orre	ation	Matrix

2·	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Age																
2. BMI	445**															
3. A1C	179	.376*														
4. Cholesterol	087	.341	.185													
5. Systolic blood pressure	.077	.325	.124	.171												
6. Diastolic blood pressure	236	.219	.206	.007	.406*											
7. Gender	.157	185	199	.203	.148	.233										
8. Diabetes education	.214	086	.016	.022	.345	019	.089									
9. Employment status	.659***	149	047	187	.144	.082	.129	.300								
10. Income	326	180	133	011	200	.059	019	170	302							
11. DDS	440**	.371*	.649***	.431	001	.143	074	249	271	.039						
12. mMOS-SSS	.143	120	300	.260	.196	.119	.205	038	.054	.408*	293					
13. SSQ6 - Persons	.178	556***	281	067	037	146	.250	013	257	.152	237	.444**	92			
14. SSQ6 - Satisfaction	.357*	235	336	.056	.405*	136	.325	.276	.187	023	431*	.546***	.482**			
15. DES-SF	.377*	186	353*	242	.148	214	.302	.285	.302	.027	419*	.285	.118	.495**	3+80	
16. SDSCA	.012	384*	380*	570*	358	354	192	179	.034	.065	291	.010	.147	.075	088	

Note:\*p<0.05; \*\*p<0.01; \*\*\*p<.001 deemed significant after Bonferroni correction. Measure abbreviations are defined as follows: DDS = Diabetes Distress Scale; mMOS-SSS = Modified Medical Outcomes Study Social Support Survey; SSQ6 = Social Support Questionnaire Short Form; DES-SF = Diabetes Empowerment Scale - Short Form; SDSCA = Summary of Diabetes Self-Care Activities.

# Table 4

Summary of Diabetes Self-Care Activities Subscale Correlations

	Cholesterol	BMI	A1C
1. Diet	357	370*	440*
2. Exercise	589*	296	464**
3. Blood sugar testing	.172	055	252
4. Foot care	480*	199	137

*Note:* \**p*<0.05; \*\**p*<0.01

# Table 5

Diabetes Distress Scale Subscale Correlations

	Age	A1C	DES-SF
1. Emotional burden	444**	.617***	565***
2. Physician-related	350*	.534***	167
3. Regimen-related	252	.756***	399*
4. Diabetes-related interpersonal	521**	.272	197

*Note:* p < 0.05; p < 0.01; p < 0.01; p < 0.01 deemed significant after Bonferroni correction



**Figure 1.** Summary of Diabetes Self-Care Activities Subscale Scores. Figure 1 displays the average number of days participants reported performance of self-care activities within each subscale. Blood glucose testing was the most frequently performed activity (mean, 5.6 days), followed by foot care (mean, 4.2 days), exercise (mean, 3.8 days), and diet (mean, 3.5 days).



**Figure 2.** Diabetes Distress Scale Scores. Figure 2 displays mean total and subscale scores on Diabetes Distress Scale for all participants. Each circle represents an individual mean score to demonstrate overall distribution of scores for total measure and each subscale. Abbreviations are defined as follows: EB = emotional burden; PD = physician-related distress; RD = regimen-related distress; ID = diabetes-related interpersonal distress. Total indicates mean scores on the full measure. Mean scores of 3 or higher indicate moderate levels of distress. Of the 33 participants, 12% scored 3 or above on the total scale, 18% scored 3 or above on EB, 21% scored 3 or above on RD, and 21% scored 3 or above on ID.



**Figure 3.** A1C vs. Regimen-Related Distress Scores. Figure 3 displays the line of best fit for the relationship between A1C and regimen-related distress scores ( $\rho = .756$ , p <.001).

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# Appendix A

#### Self-care measure

The strengths of the 11 core items of the revised SDSCA include their brevity and ease of scoring, which make them practical to use both clinically and in research. Their use in past research provides valuable information on norms, reliability, and validity, against which new data can be evaluated. The revised questionnaire is preliminary, and it needs replication and use in other samples. We have deliberately placed the SDSCA in the public domain and encourage its use.

Additional self-care items are also provided that address questions of clinical interest, but for which little or no reliability and validity data are available. Six additional items address self-care recommendations. These may be useful for clarifying patient understanding of self-management goals, as well as for evaluating congruence between perceived recommendations and reported levels of self-care (adherence). The expanded version of the SDSCA may be used when a particular question is of interest to study investigators or when time permits.

#### APPENDIX

#### The Summary of Diabetes Self-Care Activities

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

#### Diet

How many of the last SEVEN DAYS have you followed a healthful eating plan?

0 1 2 3 4 5 6 7

On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?

0 1 2 3 4 5 6 7

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#### Exercise

On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0 1 2 3 4 5 6 7 On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?

0 1 2 3 4 5 6 7

### **Blood Sugar Testing**

On how many of the last SEVEN DAYS did you test your blood sugar?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?

0 1 2 3 4 5 6 7

#### **Foot Care**

On how many of the last SEVEN DAYS did you check your feet?

0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you inspect the inside of your shoes?

0 1 2 3 4 5 6 7

### Smoking

Have you smoked a cigarette-even one puff-during the past SEVEN DAYS?

0. No

 Yes. If yes, how many cigarettes did you smoke on an average day? Number of cigarettes:

Additional Items for the Expanded Version of the Summary of Diabetes Self-Care Activities.

### Self-Care Recommendations

- 1A. Which of the following has your health care team (doctor, nurse, dictitian, or diabetes educator) advised you to do? Please check all that apply:
   □ a. Follow a low-fat eating plan
- □ b.Follow a complex carbohydrate diet
- $\Box$  c. Reduce the number of calories you
- c. Reduce the number of calories ye

eat to lose weight

- $\Box$  d.Eat lots of food high in dietary fiber  $\Box$  e.Eat lots (at least 5 servings per day)
- of fruits and vegetables f. Eat very few sweets (for example: desserts, non-diet sodas, candy bars)
- □ g. Other (specify): □ h.I have not been given any advice about
- my diet by my health care team.
- 2A. Which of the following has your health care team (doctor, nurse, dietitian or diabetes educator) advised you to do? Please check all that apply:
- a. Get low level exercise (such as walking) on a daily basis.
- b.Exercise continuously for a least 20 minutes at least 3 times a week.
- □ c. Fit exercise into your daily routine (for example, take stairs instead of elevators, park a block away and walk, etc.)
- □ d.Engage in a specific amount, type, duration and level of exercise.
- e. Other (specify):
- ☐ f. I have not been given any advice about exercise by my health care team.
- 3A. Which of the following has your health care team (doctor, nurse, dietitian, or diabetes educator) advised you to do? Please check all that apply:
- a. Test your blood sugar using a drop of blood from your finger and a color chart.
- b.Test your blood sugar using a machine to read the results.
- □ c. Test your urine for sugar.
- □ d.Other (specify):
- e.I have not been given any advice either about testing my blood or urine sugar level by my health care team.
- 4A. Which of the following medications for your diabetes has your doctor prescribed? Please check all that apply.
- $\Box$  a. An insulin shot 1 or 2 times a day.  $\Box$  b.An insulin shot 3 or more times a
- day.
   □ c.Diabetes pills to control my blood
- sugar level.
- d.Other (specify):
- e.I have not been prescribed either insulin or pills for my diabetes.

Diet

- 5A. On how many of the last SEVEN DAYS did you space carbohydrates evenly through the day?
  - 0 1 2 3 4 5 6 7

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#### Medications

6A. On how many of the last SEVEN DAYS, did you take your recommended diabetes medication?

0 1 2 3 4 5 6 7

#### OR

7A. On how many of the last SEVEN DAYS did you take your recommended insulin injections?

0 1 2 3 4 5 6 7

- 8A. On how many of the last SEVEN DAYS did you take your recommended number of diabetes pills?
  - 0 1 2 3 4 5 6 7

#### Foot Care

9A. On how many of the last SEVEN DAYS did you wash your feet?

0 1 2 3 4 5 6 7

- 10A. On how many of the last SEVEN DAYS did you soak your feet?
  - 0 1 2 3 4 5 6 7
- 11A. On how many of the last SEVEN DAYS did you dry between your toes after washing?

#### 0 1 2 3 4 5 6 7

#### Smoking

12A. At your last doctor's visit, did anyone ask about your smoking status? 0. No

1. Yes

- 13A. If you smoke, at your last doctors visit, did anyone counsel you about stopping smoking or offer to refer you to a stop-smoking program? 0. No
  - 1. Yes
  - 2. Do not smoke.
- 14A. When did you last smoke a cigarette? □ More than two years ago, or never
- smoked
- $\Box$  One to two years ago
- □ Four to twelve months ago
- □ One to three months ago
- □ Within the last month
- □ Today

#### Scoring Instructions for the Summary of Diabetes Self-Care Activities Scores are calculated for each of the five

regimen areas assessed by the SDSCA: Diet, Exercise, Blood-Glucose Testing, Foot-Care, and Smoking Status.

#### Step 1:

- For items 1–10, use the number of days per week on a scale of 0–7. Note that this response scale will not allow for direct comparison with the percentages provided in Table 1.
- Step 2: Scoring Scales
  - General Diet = Mean number of days for items 1 and 2.
  - Specific Diet = Mean number of days for items 3, and 4, reversing item 4 (0=7, 1=6, 2=5, 3=4, 4=3, 5=2, 6=1, 7=0).
  - Given the *low inter-item correlations for* this scale, using the individual items is recommended.
  - Exercise = Mean number of days for items 5 and 6.
  - Blood-Glucose Testing = Mean number of days for items 7 and 8.
  - Foot-Care = Mean number of days for items 9 and 10.
  - Smoking Status = Item 11 (0 = non-smoker, 1 = smoker), and number of cigarettes smoked per day.

### Scoring for Additional Items

- Recommended regimen = Items 1A 4A, and items 12A 14A, no scoring required.
- Diet = Use total number of days for item 5A.
- Medications = Use item 6A OR 7A AND 8A, use total number of days for item 6A, use mean number of days if both 7A and 8A are applicable. Foot-Care = Mean number of days for items 9A - 11A, after reversing 10A

and including items 9 and 10 from the brief version.

Acknowledgments — Preparation of this report was supported by National Institutes of Health Grants DK 35524 and DK 20579, and by grant 030103 from the Robert Wood Johnson Foundation.

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## **Appendix B**

DDS

## THE DIABETES DISTRESS SCREENING SCALE

**DIRECTIONS:** Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

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 circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

DDS

## DDS

**DIRECTIONS:** Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

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 circle "1". If it is very bothersome to you, you might circle "6".

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
6. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6
7. 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).	1	2	3	4	5	6
8. Feeling that diabetes controls my life.	1	2	3	4	5	6

	Not a Problem	A Slight Problem	A Moderate Problem	Somewhat Serious Problem	A Serious Problem	A Very Serious Problem
9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self management.	1	2	3	4	5	. 6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

DDS

## **DDS17 SCORING SHEET**

### **INSTRUCTIONS FOR SCORING:**

The DDS17 yields a total diabetes distress scale score plus 4 sub scale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. The letter in the far right margin corresponds to that item's subscale as listed below. We consider a mean item score of 3 or higher (moderate distress) as a level of distress worthy of clinical attention. Place a check on the line to the far right if the mean item score is  $\geq 3$  to highlight an above-range value.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored 3 or higher.

a. Sum of 17 item scores.b. Divide by:c. Mean item score:a. Sum of 5 items (1, 3, 8, 11, 14)b. Divide by:c. Mean item score: $5$ $23$	
b. Divide by: c. Mean item score: A. Emotional Burden: a. Sum of 5 items (1, 3, 8, 11, 14) b. Divide by: c. Mean item score:	
c. Mean item score: $\geq 3$ A. Emotional Burden: a. Sum of 5 items (1, 3, 8, 11, 14) b. Divide by: c. Mean item score: $\geq 3$	
A. Emotional Burden:a. Sum of 5 items (1, 3, 8, 11, 14)b. Divide by:c. Mean item score:	_
a. Sum of 5 items (1, 3, 8, 11, 14)         b. Divide by:         c. Mean item score:	
b. Divide by: $5$ c. Mean item score: $23$	
c. Mean item score: $\geq 3$	
B. Physician-related Distress:	
a. Sum of 4 items (2, 4, 9, 15)	
b. Divide by:	
c. Mean item score: $\geq 3$	_
C. Regimen-related Distress:	
a. Sum of 5 items (5, 6, 10, 12, 16)	
b. Divide by: 5	
c. Mean item score: $\geq 3$	
D. Interpersonal Distress:	
a. Sum of 3 items (7, 13, 17)	
b. Divide by: 3	
c. Mean item score: $\geq 3$	_

# Appendix C

Modified Medical Outcomes Survey Social Support Scale (mMOS-SSS)

1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)

Write in number of close friends and close relatives:

If you needed it, how often is someone available	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. To help you if you were confined to bed?	1	2	3	4	5
2. To take you to the doctor if you need it?	1	2	3	4	5
3. To prepare your meals if you are unable to do it yourself?	1	2	3	4	5
4. To help with daily chores if you were sick?	1	2	3	4	5
5. To have a good time with?	1	2	3	4	5
6. To turn to for suggestions about how to deal with a personal problem?	1	2	3	4	5
7. Who understands your problems?	1	2	3	4	5
8. To love and make you feel wanted?	1	2	3	4	5

# **Appendix D**

### Social Support Questionnaire Short Form (SSQ6)

### Instructions:

The following questions ask about people in your life who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, who you can count on for help or support in the manner described. Write the person's initials and their relation to you. Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how satisfied you are with the overall support you have. If you have no support for a question, circle the words "No one," but still rate your level of satisfaction. Do not list more than nine people per question.

Please answer all the questions the best you can. All your responses will be kept confidential.

1. Whom can you really count on to distract you from your worries when you feel under stress?

No one	1. 2. 3.	4. 5. 6.		7. 8. 9.	
How satisfied?	2				
6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 - very dissatisfied
2. Whom can or tense?	you really cou	nt on to help y	ou feel more re	elaxed when yo	u are under pressure
No one	1. 2. 3.	4. 5. 6.		7. 8. 9.	
How satisfied?	2				
6 – very satisfied	5 – fairly satisfied	4 – a little satisfied	3 – a little dissatisfied	2 – fairly dissatisfied	1 - very dissatisfied

3. Whom accepts you totally, including both your worst and your best points?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied?

6 – very	5 – fairly	4 – a little	3 – a little	2 – fairly	1 - very
satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

4. Whom can you really count on to care about you, regardless of what is happening to you?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied?

6 – very	5 – fairly	4 – a little	3 – a little	2 — fairly	1 - very
satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

5. Whom can you really count on to help you feel better when you are feeling generally downin-the-dumps?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied?

6 – very	5 – fairly	4 – a little	3 – a little	2 – fairly	1 - very
satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied
6. Whom can you count on to console you when you are very upset?

No one	1.	4.	7.
	2.	5.	8.
	3.	6.	9.

How satisfied?

6 – very	5 – fairly	4 – a little	3 – a little	2 — fairly	1 - very
satisfied	satisfied	satisfied	dissatisfied	dissatisfied	dissatisfied

## Appendix E

I am going to read you some statements about diabetes. Each statement finishes the sentence "In general, I believe that..." The response categories are: **Strongly Disagree, Somewhat Disagree, Neutral, Somewhat Agree, and Strongly Agree.** It is important that you answer <u>every</u> statement.

## **Attitudes Toward Diabetes – DES**

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
In general, I believe that I:					
<ol> <li>know what part(s) of taking care of my diabetes that I am <b>dissatisfied</b> with.</li> </ol>	( )	( )	( )	( )	( )
<ol> <li>am able to turn my diabetes goals into a workable plan.</li> </ol>	( )	( )	( )	( )	( )
<ol> <li>can try out different ways of overcoming barriers to my diabetes goals.</li> </ol>	( )	( )	( )	( )	( )
4can find ways to feel better about <b>having</b> diabetes.	( )	( )	( )	( )	( )
<ol> <li>know the <b>positive</b> ways I cope with diabetes-related stress.</li> </ol>	( )	( )	( )	( )	( )
<ol> <li>can ask for support for having and caring for my diabetes when I need it.</li> </ol>	( )	( )	( )	( )	( )
<ol> <li>know what helps me stay motivated to care for my diabetes.</li> </ol>	( )	( )	( )	( )	( )
8know enough about my- self as a person to make diabetes care choices that are right for me.	( )	( )	( )	( )	( )