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Diabetes is a complex, chronic condition that affects over 30 million people, with increased prevalence in non-Hispanic Black adults. Engagement in the self-care of diabetes is necessary to prevent complications and maintain stability. In addition to these changes, the emotional response associated with diabetes, diabetes distress, can influence one’s self-care of diabetes. Recognizing that diabetes distress can impact one’s ability to manage self-care activities, the concept of diabetes distress should be considered when studying self-care behaviors. The purpose of this study was to (a) describe the concepts of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress and its subscales (emotional burden, physician distress, regimen distress, and interpersonal distress) in non-Hispanic Black adults ages 18-64 years old living with type 2 diabetes (T2DM) in North Carolina and (b) to ascertain if there are relationships between and among the concepts self-care of diabetes and diabetes stress and its subscales in the same population.

A cross-sectional correlational design was conducted utilizing a confidential online survey accessed via a QR code or a URL link. A convenience sampling method was used, and participants were recruited from community-based settings. An investigator-designed questionnaire collected sociodemographic and clinical characteristics data. The self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress were measured using the Self-Care of Diabetes Inventory and the Diabetes Distress Scale 17. Descriptive statistics and median regression were used to describe the study sample and answer the research questions.

A total of 310 participants met the eligibility criteria for the study, and 275 took the online survey. In this sample of non-Hispanic Black adults, the level of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) was less than adequate, and the participants experienced moderate to high levels of diabetes distress. The findings demonstrated a positive association between total diabetes distress score and self-care monitoring and self-care management (with and without insulin use), indicating that as diabetes distress increased, so did the level of self-care of diabetes. Income, last self-reported HbA1c, and the number of diabetes-related comorbidities showed a statistically significant association with self-care maintenance, self-care monitoring, and self-care management (with and without insulin use) scores. The total diabetes distress score showed a statistically significant association with self-care monitoring and self-care management (with and without insulin use). The diabetes distress subscales did not show a statistically significant association with the self-care of diabetes. Previous studies showed as diabetes distress increased, diabetes self-care behaviors decreased, contributing to poor glycemic control and poorer health outcomes. The findings indicate the need for more studies to examine the relationship between self-care of diabetes and diabetes distress in non-Hispanic Black adults living with type 2 diabetes.

Understanding the relationship between diabetes distress and the self-care of diabetes is crucial in addressing diabetes-related complications leading to poorer health outcomes in this population. Knowledge about the level of self-care of diabetes and diabetes distress and the relationship between self-care of diabetes and diabetes distress was gained in this sample of non-Hispanic Black adults ages 18-64 living in North Carolina. The findings of this study will inform clinical practice, education, recruitment strategies, and future research for non-Hispanic Black adults with diabetes.

THE RELATIONSHIP BETWEEN SELF-CARE OF DIABETES AND DIABETES DISTRESS IN NON-HISPANIC BLACK ADULTS LIVING WITH TYPE 2 DIABETES

by

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Dr. Laurie Kennedy-Malone
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DEDICATION

To Mommy, Daddy, Family, and Friends,

Mommy (Veronica Rochelle Neblett), there are not enough words to express my heartfelt gratitude for all your love, support, and prayers during my Ph.D. journey, especially the last several weeks of recruitment, data analysis, and writing. I am blessed to have you. I love you.

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I could have never accomplished this goal without GOD and each of you.

Grace and Peace.

For I know the plans I have for you,” declares the Lord, “plans to prosper you and not to harm you, plans to give you hope and a future. Jeremiah 29:11

APPROVAL PAGE

This dissertation written by Debra Anita Neblett has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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CHAPTER I: INTRODUCTION

Diabetes is a complex, chronic condition that can cost individuals physically, emotionally, and financially. Before 2020, diabetes was the seventh leading cause of death in the United States for over ten years (Heron, 2013; Murphy et al., 2021). Diabetes is a progressive metabolic disorder resulting in hyperglycemia and adverse effects on multiple organ systems. There are several categories of diabetes, but the most common are type 1 diabetes, type 2 diabetes, and gestational diabetes. Type 1 diabetes is an absolute insulin deficiency. Gestational diabetes is diagnosed in the second or third trimester of pregnancy and can later increase the risk of developing type 2 diabetes (American Diabetes Association Professional Practice Committee, 2021a). Type 2 diabetes is the progressive loss of beta-cell insulin secretion and insulin resistance. Type 2 diabetes (T2DM) accounts for 90-95% of all cases of diabetes (American Diabetes Association [ADA], 2018a).

The management of T2DM is multifaceted, and most of the care is provided by individuals living with diabetes (American Diabetes Association Professional Practice Committee, 2021c). Significant adjustments to the individual’s lifestyle are necessary to prevent complications and maintain stability, such as changes to diet, physical activity, taking medications, checking glucose, checking feet, annual screenings, and periodic lab tests. The self-management also referred to as self-care, rests in the hands of the individual and sometimes a support person (Jaarsma et al., 2020). Limited studies explicitly assess self-care of diabetes comprehensively in non-Hispanic Black adults living with T2DM (Adjei Boakye et al., 2018; Hernandez et al., 2020; Miller et al., 2015). Given the number of changes needed, individuals can experience increased emotional distress associated with the diagnosis of diabetes, which is referred to as diabetes distress (Fisher et al., 2010; Polonsky et al., 1995, 2005). The consistent self-care of diabetes and assessment of diabetes distress in individuals living with T2DM can lead to improved health outcomes (Ausili et al., 2018; Fisher et al., 2019; Polonsky et al., 1995, 2005).

Background

Diabetes is a global, national, and regional concern. The estimated number of adults with diabetes is 422 million worldwide, 29 million in the United States, and 887,000 in North Carolina (American Diabetes Association, 2022; United Health Foundation, n.d.-a; World Health Organization, 2021). Increasing age, obesity, lack of physical activity, history of gestational diabetes, hypertension, hyperlipidemia, certain racial/ethnic groups, and family history in a first-degree relative increase the risk of developing T2DM. Most individuals with T2DM are overweight or obese with a BMI ≥ 25 kg/m^2. Some individuals have a lower BMI but generally increased body fat in the abdominal area (American Diabetes Association Professional Practice Committee, 2021a). Obesity is a chronic condition, and the prevalence of obesity is trending upward and is 42.4% in U.S. adults. Non-Hispanic Black adults have the highest prevalence of obesity (49.6%) compared to other races and Hispanic ethnic groups. The prevalence of obesity is 40-44.8% in all non-Hispanic Black adult age groups and highest in 40-59-year-olds (Centers for Disease Control and Prevention, 2021). The American Diabetes Association recommends screening for T2DM begin at 35 and at any age in adults who are overweight or obese with one or more risk factors (American Diabetes Association Professional Practice Committee, 2021a).

The percentage of adults who reported being told they had diabetes, excluding gestational and prediabetes, by a health professional was 11.3% in the United States in 2017-2020 and 12.7% in non-Hispanic Blacks (Centers for Disease Control and Prevention, 2022a). Non-Hispanic Black adults are 60% more likely to be diagnosed with diabetes by a healthcare provider than non-Hispanic whites (U.S. Department of Health and Human Services, n.d.). The prevalence of diabetes from highest to lowest according to race and ethnicity is American Indians/Alaska Natives, non-Hispanic Blacks, Hispanics, Asians, and non-Hispanic Whites. The 2018-2019 estimated prevalence of diagnosed diabetes by race/ethnicity and sex in adults ≥18 years of age was 12.1% of non-Hispanic Black males and females compared to 8.0% of non-Hispanic White males and 6.9% of non-Hispanic White females (CDC, 2022a).

Non-Hispanic Black adults are 13.4% of the population but account for 12.7% of adults diagnosed with diabetes. They are less likely to have the recommended glycosylated hemoglobin (HbA1c) of <7% compared to non-Hispanic White adults (American Diabetes Association, 2018a; Centers for Disease Control and Prevention [CDC], 2020, 2022c; U.S. Census Bureau, n.d.). Diabetes-associated complications occur more frequently in non-Hispanic Blacks than non-Hispanic Whites (U.S. Department of Health and Human Services, n.d.). Hospitalizations for lower-limb amputations were 2.3 times more likely in non-Hispanic Black adults (CDC, 2022b). They were also 3.2 times more likely to be diagnosed with end-stage renal disease than non-Hispanic Whites (U.S. Department of Health and Human Services, n.d.). In addition to complications and disabilities associated with diabetes, mortality in non-Hispanic Blacks is increased, and they are twice as likely as non-Hispanic Whites to die from diabetes (Murphy et al., 2021; U.S. Department of Health and Human Services, n.d.).

Diabetes deaths per 100,000 standard population increased from 21.6 to 24.8 in 2020, which is a 14.8% increase (Murphy et al., 2021). Data provided in Health, United States, 2019 reported the leading causes of death by sex, race, and Hispanic origin in the United States between 1980 and 2018. Diabetes remained the seventh leading cause of death in non-Hispanic Whites for both years, while in non-Hispanic Blacks, diabetes was the eighth leading cause of death in 1980 and increased to the fifth leading cause of death in 2018 (National Center for Health Statistics, 2021). The number of 2019 deaths in the United States from diabetes increased by 3.2% compared to 2018 and by 4.1% in ages 45-64 (Heron, 2021).

North Carolina is one of the ten states with the largest non-Hispanic Black population, and they are 22% of the state's population (United Health Foundation, n.d.-b; U.S. Department of Health and Human Services, n.d.; World Population Review, 2022). In North Carolina, 12.4% of the adult population reported being diagnosed by a health professional with diabetes compared to 10.6% of adults in the United States (American Diabetes Association, 2022; United Health Foundation, n.d.-a). Overall mortality rates from 2012 to 2016 due to diabetes were 23 for the general population in North Carolina, 18.8 in Whites, and 44.0 in African Americans, with a disparity ratio of 2.3 (NC Department of Health and Human Services, 2018). Whites were 66.4% of the people of North Carolina, and African Americans were 22.1% based on 2016 population estimates (N.C. Department of Health and Human Services, 2018).

Significance of the Problem

Adults diagnosed with diabetes have an increased all-cause mortality of 1.8 times compared to adults not diagnosed with diabetes (Office of Disease Prevention and Health Promotion, n.d.-a). Non-Hispanic Black adults are 1.7 times more likely to have diabetes, increasing the risk of chronic comorbidities and increased susceptibility to infections (CDC, 2022c; U.S. Department of Health and Human Services, n.d.-a). Diabetes is described as the most expensive chronic condition in the United States. The cost of diagnosed diabetes has increased by 26%, from $245 billion in 2012 to $327 billion in 2017 (ADA, 2018b).

The healthcare cost spent on adults with diabetes is $1 out of $4 in the United States (National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP], 2022;

Riddle & Herman, 2018; Zhuo et al., 2014). In 2017, North Carolina's total direct medical expenditures for diagnosed diabetes were $7.7 billion. Indirect costs from lost productivity due to diabetes were $2.9 billion (ADA, 2022).

The staggering costs of diabetes management and the treatment of diabetes complications highlight the need for high-quality interventions that include electronic health information, interprofessional healthcare teams, disease management, clinical decision-making, and individual self-management, support, and education (Riddle & Herman, 2018). Several barriers can impact the effective management of diabetes.

Some barriers for non-Hispanic Black adults include access to quality health care, access to healthy foods, socioeconomic challenges due to the salary divide compared to non-Hispanic whites, adherence to healthy food choices, cost of treatment, medication adherence, physical activity, and access to quality diabetes-specific health care (Akindana & Ogunedo, 2015). In 2019, private insurance was used by 55.9% of non-Hispanic Blacks compared to 74.7% of non-Hispanic Whites; Medicaid or public insurance was used by 43.5% of non-Hispanic Blacks and 34.3% of non-Hispanic Whites (U.S. Department of Health and Human Services, n.d.). The average non-Hispanic Black median house income in 2019 was $43,771 compared to $71,664 for non-Hispanic White.

The social determinants of health (SDOH) are other potential barriers. The World Health Organization describes the SDOH as “ the non-medical factors that influence health outcomes” (World Health Organization, n.d.). Healthy People 2030 characterizes SDOH as “the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning and quality of life outcomes and risks (Office of Disease Prevention and Health Promotion, n.d.-b). The social determinants of health include education, food insecurity, access to healthy food options, unemployment, and job insecurity, income, safe housing, environment (clear air and water), and access to affordable quality health care (Office of Disease Prevention and Health Promotion, n.d.-b; World Health Organization, n.d.).

The rate of uninsured Black Americans under 65 has decreased since the implementation of the Affordable Care Act. It dropped to 12% in 2019 compared to 20% in 2011, but this rate is still lower than White Americans. Of note, the expansion of Medicaid has not occurred in twelve states, including North Carolina. Many Southern states have large non-Hispanic Black populations (U.S. Department of Health and Human & Services, 2022). The highlighted disparities can influence the self-care of diabetes and increase the likelihood of emotional distress related to diabetes (Bhattacharya, 2012a; Hawkins et al., 2015; Hernandez et al., 2014; Hood et al., 2018).

Self-Care of Diabetes

Lifestyle modification and diabetes education are the foundation of diabetes management regardless of the pharmacologic interventions. Positive health behaviors and psychological well-being are essential for achieving diabetes treatment objectives and maximizing quality of life (American Diabetes Association Professional Practice Committee, 2021c). Diabetes self-management education and support (DSMES) are vital to meet these goals (ADA, 2018b; Purvis et al., 2022). Decision-making, self-care practices, problem-solving, and active cooperation with the healthcare team are all components of DSMES, aiming to enhance health status, clinical results, and well-being (American Diabetes Association Professional Practice Committee, 2021c; Powers et al., 2020). Engagement in the self-care of diabetes is necessary for long-term diabetes management because it allows lifestyle modifications to be integrated into the daily lives of individuals with diabetes. The ADCES7 Self-Care Behaviors™ is a framework for behavior change that can lead to effective self-management through improved behavior and clinical outcome measurements, according to the Association of Diabetes Care and Education Specialists (ADCES). The ADCES7 Self-Care Behaviors™ include healthy coping, healthy eating, being active, taking medication, monitoring, reducing risk, and problem-solving (Association of Diabetes Care and Education Specialists, 2021).

The importance of self-care in chronic conditions has been widely recognized and discussed in the literature for a long time (Denyes et al., 2001; Jaarsma et al., 2020; Matarese et al., 2018; Wilkinson & Whitehead, 2009). Still, there is limited evidence to validate its long-term influence on health outcomes (Jaarsma et al., 2020). Various instruments are used to measure diabetes self-care behaviors in studies for assessment and pre/post-intervention evaluations. There is an opportunity to expand the comprehensive assessment of self-care of diabetes behaviors in all individuals, particularly in non-Hispanic Black adults with type 2 diabetes (T2DM).

As a result of the rising expense of diabetes management, diabetes-related complications, and disability resulting from the increasing prevalence of diabetes globally, nationally, and regionally, diabetes can be considered an epidemic (CDC, 2022c; NCCDPHP, 2022; WHO, 2021). The self-care of T2DM is overwhelming for the general population but even more so in underrepresented communities such as non-Hispanic Blacks (Bhattacharya, 2012b; Helgeson et al., 2021; Presley et al., 2021; Sherman & Williams, 2018). Self-care of diabetes is complex and demands constant vigilance to prevent and delay complications. Individuals living with T2DM who are incorporating diabetes self-care behaviors such as daily blood glucose monitoring can experience a sense of hopelessness, anxiety, and fear. This emotional response has been coined diabetes distress (Fisher et al., 2010; Polonsky et al., 1995, 2005).

Diabetes Distress

According to a meta-analysis, 36% of individuals living with T2DM experienced emotional distress related to diabetes (Perrin et al., 2017). The fears, concerns, anxiety, and threats associated with this progressive chronic disease, complications, disability, and access to quality health care are described as diabetes (Fisher et al., 2010, 2019; Hernandez et al., 2020; Parsa et al., 2019; Perrin et al., 2017; Polonsky et al., 1995, 2005). Diabetes distress can be described as an emotional effect of having diabetes and is an expected response (Fisher et al., 2010, 2019; Polonsky et al., 1995, 2005). Many individuals living with diabetes struggle with self-management, also referred to as self-care. The duration of diabetes, type of diabetes, associated complications, medication regimen, age, gender, and ethnicity can influence how an individual manifests diabetes distress. Some examples are fear of adverse reactions to treatment, such as hypoglycemia, loss of control, hopelessness, and burnout related to the constant vigilance needed for self-management (Fisher et al., 2019; Perrin et al., 2017).

Studies indicate a relationship between the duration of diabetes, family history of diabetes, treatment regimen, relationship with the health care provider, and diabetes distress (Hernandez et al., 2020; Parsa et al., 2019). One study identified clinical determinants such as elevated HbA1c, body mass index (BMI), and triglycerides that can predict diabetes distress (Parsa et al., 2019). Participants desired more emphasis on how they coped with diabetes versus a review of lab results during encounters (Hernandez et al., 2020). Another study examining diabetes distress and social support in adults with T2DM found that participants with low social support are more likely to experience severe diabetes distress associated with inadequate diabetes self-management (Presley et al., 2021). The population for this study was non-Hispanic Black adults 18-64 years old living with T2DM in North Carolina.

Statement of the Problem

The prevalence of diabetes, rate of diabetes complications, and increased mortality in non-Hispanic Black adults living with T2DM are staggering. Self-care, also called self-management, has a significant role in managing chronic diseases such as diabetes (American Diabetes Association Professional Practice Committee, 2021c; Kolb, 2021). Inconsistent diabetes self-care is linked to adverse outcomes such as cardiovascular disease, stroke, blindness, and lower-extremity amputations. Ongoing assessment and evaluation of self-care of diabetes in all individuals with diabetes, particularly in populations disproportionately affected by T2DM, can assist healthcare providers and researchers in providing care and developing culturally specific interventions. In addition, studies highlight the challenges and inconsistent practice of self-care of diabetes in individuals living with T2DM (Al-Khawaldeh et al., 2012; Mayberry et al., 2016; Murrock et al., 2013; Shrivastava et al., 2013). The literature includes numerous studies about self-care behaviors and self-management in individuals with diabetes, but the measurement is not comprehensive with limited use of theoretical frameworks (Adjei Boakye et al., 2018; Ausili et al., 2018; Hernandez et al., 2020; Luciani et al., 2021; Miller et al., 2015). The concept of self-management is used broadly and often puts all self-care behaviors together with limited emphasis on decision-making (Riegel et al., 2012, 2018, 2019). Self-care of diabetes in non-Hispanic Black adults is described as inconsistent (Chlebowy et al., 2010; Hawkins, 2019; Murrock et al., 2013; Nelson et al., 2019). For example, eating behaviors, physical activity, and medication adherence may be measured but not self-monitoring or decision-making. Various instruments are used in studies, and few are guided by a theoretical framework in their development (Lee et al., 2020). As a result, a complete picture may not be obtained, which can pose challenges for creating interventions to support the improved engagement of non-Hispanic

Black adults in self-care behaviors to improve and sustain better health outcomes. The use of theoretical frameworks or the ADCES7 Self-Care Behaviors™ in studies is limited. The practice of self-care of diabetes is essential in the management of T2DM.

Individuals living with diabetes are at risk for distress, life stress, and clinical depression, resulting in poor health outcomes (Davis et al., 2022). Limited quantitative studies examine diabetes distress, specifically in non-Hispanic Black adults. Still, the findings of the studies demonstrate that increased diabetes distress has a negative influence on engagement in self-care of diabetes, contributing to poorer health outcomes (Bhattacharya, 2012a; Chlebowy et al., 2010; Hernandez et al., 2014; Hoogendoorn et al., 2020). A two-phase mixed-methods sequential explanatory study was conducted to understand diabetes-related distress (DRD) characteristics and identify the psychological support preferences of urban African American adults living with T2DM. The quantitative results suggested that participants had moderate DRD, further described as regimen distress and emotional distress. The qualitative results indicated participants wanted providers to address mental health care related to living with T2DM and voiced the need for culturally appropriate peer groups, including gender and age-specific groups (Hood et al., 2018). More studies examining self-care of diabetes in non-Hispanic Black adults are needed, along with a better understanding of the relationship between diabetes self-care and diabetes distress. Therefore, this study sought to describe diabetes self-care and diabetes distress in non-Hispanic Black adults with T2DM and examine the relationship between self-care of diabetes and diabetes distress.

Purpose of the Study

The purpose of this study was to (a) describe the level of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and the level of diabetes distress in non-Hispanic Black adults ages 18-64 years old living with T2DM in North Carolina and (b) to ascertain if there are relationships between and among the concepts self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress in the same population.

The Theoretical Framework

Theory of Self-Care of Chronic Illness

Self-care has been discussed in the literature for many years (Denyes et al., 2001; Orem et al., 2003; Richard & Shea, 2011; Riegel et al., 2012, 2018; Wilkinson & Whitehead, 2009). Studies examining self-care and heart failure are prominent (Carlson et al., 2001; Riegel et al., 2009, 2016). Dr. Riegel and colleagues' work with heart failure patients resulted in a situation-specific theory for heart failure self-care, which led to the development of the *Theory of Self-Care of Chronic Illness*. Their work has resulted in a plethora of research on heart failure self-care utilizing this theoretical framework and measuring heart failure self-care using instruments guided by the theory (Hägglund et al., 2019; Jaarsma et al., 2017; Riegel et al., 2016; Woda et al., 2015).

The *Theory of Self-Care of Chronic Illness* is a middle-range theory. A middle-range theory is a fundamental, practical framework of ideas that is less abstract than grand theory but more abstract than empirical generalizations or microrange theory (Smith & Liehr, 2018). This middle-range theory provides a holistic view of individuals with multiple chronic illnesses (Riegel et al., 2012; Riegel et al., 2018). This model can be applied to other chronic illnesses, such as diabetes (Riegel et al., 2016). Dorothea Orem’s grand theory, the theory of self-care deficit theory, influenced its development (Riegel et al., 2012).

Riegel et al. (2019) define self-care as a process through which individuals participate in health-promoting or self-care behaviors to manage illness. This middle-range theory focuses on the self-care process of chronic illness, indicating it is a lifetime process. The theory aims to equip individuals with chronic illness to identify the gaps in their self-care and decision-making skills (Riegel et al., 2012, 2018). The theory provides a holistic approach to assessing self-care. It can provide a framework to support a better understanding of self-care of diabetes in non-Hispanic Black adults with T2DM. Type 2 diabetes affects the entirety of an individual's being, so its management requires total engagement.

Self-care is described as the primary construct of the theory (Riegel et al., 2018). Self-care occurs when individuals living with a chronic illness are stable and unstable, encouraging continuous active involvement in chronic illness management (Riegel et al., 2012). The theory's concepts are self-care maintenance, self-care monitoring, and self-care management. Recently, two areas of the *Theory of Self-Care of Chronic Illness* were identified for further development: the influence of symptoms on self-care monitoring and the relationship between self-care monitoring and self-care management. As a result, a revision of the theory was proposed to integrate symptoms with the self-care behaviors of self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2019). This revision provided additional variables to examine and explore relationships for developing targeted self-care interventions.

Concepts of the Theory of Self-Care of Chronic Illness

Self-Care Maintenance. Individuals with chronic illness carry out self-care maintenance behaviors to maintain physical and mental well-being that preserve or improve health. These behaviors include eating and preparing healthy foods, coping, physical activity, smoking cessation (health-promoting), and taking prescribed medications as directed (illness-related behaviors; Riegel et al., 2018). Individuals' reflection that behavior is purposeful supports their commitment to perform or carry out behaviors. The ongoing assessment of the benefits and effectiveness of self-maintenance behaviors helps their engagement (Riegel et al., 2012, 2018). Self-care maintenance is the foundation as individuals are provided the initial tools to begin the process. Diabetes self-care maintenance behaviors are daily self-foot checks, 150 minutes of moderate physical activity per week, healthy eating plans with reduced intake of carbohydrates, taking medications as prescribed, smoking cessation, and emotional well-being (ADA, 2021; Fisher et al., 2019; Kolb, 2021). Each self-care behavior is performed regularly, is health-promoting and illness-related, and can influence health care outcomes. Self-care maintenance includes educating individuals living with T2DM about the skills needed to perform diabetes self-care behaviors. Maintaining health and preventing exacerbations of chronic illness is the goal of self-care maintenance.

Self-Care Monitoring. Observing oneself for changes in signs and symptoms of a condition is self-care monitoring and requires surveillance, routine body monitoring, or "body listening." The emphasis is on the recognition that a change has occurred. For self-care monitoring to be effective, specific criteria must be met. First, the individual must understand the condition can change over time. Second, there must be a reliable method for detecting changes. Lastly, the individual must have a reasonable action plan to respond to the change (Riegel et al., 2012). The idea or process for monitoring is common. Individuals visit the dentist to check for cavities or monitor the status of gum disease, and individuals with heart failure monitor weight for increases and decreases. Therefore, self-care monitoring is part of the daily routine and is intentional. The best outcomes in the *Theory of Self-Care of Chronic Illness* occur with systematic and routine monitoring. The response to the signs and symptoms observed in self-care management requires evaluating the changes and beginning the decision-making process (Riegel et al., 2012, 2018). Diabetes self-care monitoring behaviors are self-monitoring blood glucose and recording results, checking and recording blood pressure, and self-foot checks to monitor for redness or breaks in the skin. Additional diabetes monitoring activities are healthcare provider foot exams, dilated eye exams, and lab monitoring for microalbuminuria, HbA1c, and lipid profile. Although these are clinical indicators, individuals should know their clinical indicators as part of their diabetes self-care.

The revised model for the *Theory of Self-Care of Chronic Illness* includes influencing factors, the integration of symptom theory, and outcomes. Experience and skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, support from others, and access to care are influencing factors or factors affecting self-care (Riegel et al., 2012, 2018). The revised model includes the integration of symptoms. Observing oneself for changes in signs and symptoms is self-care monitoring, leads to evaluation and decision-making, and is part of self-care management. Integrating symptom detection, interpretation, and response enhances the *Theory of Self-Care of Chronic Illness*. Self-care monitoring provides individuals living with T2DM the knowledge about “body listening” or self-monitoring and begins the decision-making process about actions needed. They interact with all theory concepts, specifically self-care monitoring and self-care management (Riegel et al., 2019). Recognizing a change has occurred is the goal of self-care monitoring and links self-care maintenance and self-care management.

Self-Care Management. Effective treatment of symptoms is the goal of self-care management. The individual’s response to signs and symptoms is self-management, which involves evaluating changes in emotional and physical signs and symptoms to decide if action is required (Riegel et al., 2012, 2018). Self-care proficiency helps one understand the meaning of changes resulting from illness, medical regimen, or the environment. The self-care process includes decision-making in real-time, the individual’s response to changes such as hypoglycemia, and evaluating the effectiveness of any action taken to alleviate their symptoms or improve their condition (Riegel et al., 2012, 2019). In self-care management, the action taken by an individual may require consultation with the health care provider unless the individual can independently make changes to the regimen. Self-care management combines the skills and knowledge of individuals with T2DM established during self-care maintenance and self-monitoring. A sequence or pattern is seen with self-care behaviors that build self-care maintenance. Individuals continue developing skills and knowledge in monitoring and self-care management once mastery is achieved. As a result, individuals who perform all behaviors related to the concepts are proficient in self-care.

Self-care confidence is identified as an influencing factor but not a theoretical concept. Studies generally refer to self-care confidence as self-efficacy and describe it as a moderating variable because it can affect an individual’s self-care practice positively or negatively (Al-Khawaldeh et al., 2012; Ausili et al., 2018; Riegel et al., 2012). Other influencing factors for self-care are experience and skills, motivation, cultural beliefs and values, habits, functional cognitive ability, support, and access to care (Riegel et al., 2012).

Integrating symptoms can lead to interventions that acknowledge that symptoms occur and influence an individual’s self-care behaviors and health outcomes. Intended outcomes of self-care are the stability of chronic illness, improved quality of life, perceived control over chronic illness, less anxiety associated with chronic illness, decreased hospitalizations, decreased costs, and reduced mortality and disability (Riegel et al., 2012, 2019). Unintended self-care outcomes are failure or delay in seeking care, denial, increased burden, or distress associated with daily engagement in self-care (Riegel et al., 2012).

Assumptions

The *Theory of Self-Care of Chronic Illness* had three underlying assumptions initially and was later revised (Riegel et al., 2012). First, general self-care and illness self-care are different. General self-care is influenced by gender, age, culture, and socioeconomic status. Illness-specific self-care is influenced by healthcare providers and impacts quality of life, symptom management, and health outcomes. Second, decision-making and problem-solving skills are needed in the self-care process. Third, the self-care of multiple chronic illnesses can be challenging for individuals when viewed as separate, requiring different self-care practices (Riegel et al., 2012, 2018).

The revised assumptions emphasized general and illness self-care, as discussed above. The second assumption focused on forming a partnership between the healthcare provider and individuals with chronic illnesses to inspire them to engage in self-care that can realistically be integrated into their daily lifestyle (Riegel et al., 2018).

Propositions

The theory's propositions center around themes such as the ability of self-care concepts to be translated across chronic illnesses, the influence of past self-care experiences, and self-care as an intentional learned process. Miscommunication between healthcare providers and individuals can result in insufficient self-care. Self-care maintenance and self-care monitoring behaviors are essential and demonstrate self-care management proficiency. Evidence-based self-care results in better outcomes. Additionally, mastery of one theory concept is inadequate (Riegel et al., 2012).

The *Theory of Self-Care of Chronic Illness* brings the broad topic of self-care to a level where it can be operationalized in individuals living with diabetes for research, development of interventions in clinical practice, and evaluation (Jaarsma et al., 2020). The theory can be adapted to any chronic illness, particularly T2DM or individuals with multiple comorbidities. It allows self-care to be addressed broadly with multiple comorbidities, specifically like the situation-specific theory of heart failure self-care (Riegel et al., 2016). Self-maintenance, self-care monitoring, and self-care management can be evaluated together, or each concept can be examined individually if an area of concern is identified (Ausili et al., 2017).

Summary

Type 2 diabetes (T2DM) is one of the most expensive chronic conditions in the United States and one of the leading causes of death in the United States (NCCDPHP, 2022). It is the fifth leading cause of death in non-Hispanic Black adults (National Center for Health Statistics, 2021). The prevalence of T2DM in non-Hispanic Black adults identifies the necessity for supporting non-Hispanic Black adults in the practice of self-care of diabetes guided by a theoretical framework.

Riegel's *Theory of Self-Care of Chronic Illness* guided the assessment of diabetes self-care behaviors in non-Hispanic Black adults living with T2DM for the future development of targeted evidence-based, culturally appropriate interventions to improve health outcomes (Riegel et al., 2012, 2018). It was selected because it brings the broad topic of self-care to a level that can be operationalized in individuals living with T2DM. All the concepts (self-care maintenance, self-care monitoring, self-care management) can be measured and then examined individually.

This study assessed and described diabetes self-care and diabetes distress in non-Hispanic Black adults 18-64 years old living with T2DM in North Carolina. It also examined if there was an association between diabetes self-care and diabetes distress. This chapter provided an introduction, background, statement of the problem, the purpose of the study, theoretical framework, and the significance of the study.

CHAPTER II: REVIEW OF THE LITERATURE

Self-care of diabetes includes healthy eating, being active, taking medications, monitoring blood glucose, reducing risk, and problem-solving (Association of Diabetes Care and Education Specialists, 2021). Measuring the frequency of some or all of these behaviors is essential in supporting the achievement of glycemic goals and delaying and preventing diabetes-related complications. This review will present an overview of literature describing and examining diabetes self-care and diabetes distress in non-Hispanic Black adults. Additionally, how diabetes distress, a concept introduced in the literature in the mid-1990s, affects the ability to manage self-care will be presented (Polonsky et al., 1995).

The review will synthesize the published literature describing and examining the relationship between diabetes self-care and diabetes distress in non-Hispanic Black adults with T2DM. The research about self-care of diabetes and diabetes distress crosses all disciplines, nursing, public health, medicine, psychology, social work, sociology, etc. The searches were conducted using CINAHL (Cumulative Index to Nursing and Allied Health Literature), APA PsycInfo (Psychology Information), ProQuest, EBSCOhost, Scopus, CDC libraries, Google Scholar, and PubMed. A five-year timeframe for the search was initially used to obtain the most current literature, but it was necessary to broaden the timeframe to yield more results. Many studies included references with a broader timeframe due to limited studies specific to this population. In addition to the timeframe and population of interest, searches were limited to the United States, the English language, adults 18 years old and older, and peer-reviewed publications. The searches were conducted using the following keywords: *self-care, self-care behaviors, self-care management, self-management, self-care monitoring, self-care maintenance, diabetes distress, diabetes-related stress, psychosocial stress, Type 2 diabetes, T2DM, type 2*

DM, Blacks, African Americans, or non-Hispanic Black adults. Non-interventional studies specific to non-Hispanic Blacks and those that included the population in studies were included in the literature review. In addition to the search terms listed above, articles were also found by reviewing the reference list of key publications.

Self-Care of Diabetes

Non-Hispanic Black adults have an increased prevalence of diabetes and experience increased diabetes-related complications and mortality. Individuals who do not incorporate diabetes self-care, also known as diabetes self-management, have an increased risk of diabetes-related complications, hospitalizations, disability, and mortality (Centers for Disease Control and Prevention, 2022b; Murphy et al., 2021; Pippitt et al., 2016). The practice of diabetes self-care can prevent and delay these adverse outcomes and support health outcomes by achieving recommended glycemic goal of HbA1c of <7% in addition to target goals for blood pressure, cholesterol, eye, and foot exams, screening for renal disease (American Diabetes Association Professional Practice Committee, 2021b, 2021c, 2021d).

Exploring Self-Care of Diabetes

Many studies that describe, explore, or examine diabetes self-care are qualitative in design, as evidenced by the systematic review conducted by (Majeed-Ariss et al., 2015). This review included empirical studies since 1986 to synthesize black and minority ethnic patients' views on barriers and facilitators influencing the self-management of T2DM. Over 15,000 articles were identified, with 57 used in the review. The research methods for the fifty-seven articles were qualitative (54), mixed methods (2), and quantitative (1). Findings identified decreased adherence to checking blood glucose, dietary recommendations, understanding of a healthy diet, and decreased physical activity. There was a perceived reduced knowledge regarding the relationship between glycemic control and potential diabetes-related complications (Majeed-Ariss et al., 2015).

Studies with non-Hispanic Black males and females and gender-specific studies were included in this review. The number of participants ranged from 12-84, with an age range of 18-89 years old and a duration of diabetes from one year to thirty-five years. The qualitative studies' themes consisted of individual and external factors. Individual factors were decreased understanding of the chronicity of T2DM and the demands of daily management (eating habits, physical activity, self-monitoring of blood glucose, taking medications, etc.). The risk of complications if glycemic targets are not met and maintained, the emotional stress of living with diabetes, and the fear of the unknown were also internal factors (Bhattacharya, 2012a; Bockwoldt et al., 2016; Chlebowy et al., 2013; Murrock et al., 2013; Onwudiwe et al., 2011; Sherman et al., 2014; Sherman & Williams, 2018). External factors were related to healthcare provider advice about self-care, social support, health insurance that provided care access, medications, and diabetes supplies (Chlebowy et al., 2013; Lee et al., 2016; Lynch et al., 2012; Sherman et al., 2014). The individual’s practice of diabetes self-care is necessary in times of stability and instability of a chronic illness (Riegel et al., 2018). The participants provided valuable information about their experiences living with diabetes. Diabetes self-care was not always viewed as an ongoing process that needed constant vigilance.

Chlebowy et al. (2013) examined whether gender differences in facilitators and barriers to diabetes self-management exist among African Americans living with T2DM. Participants (*n=38;* 27 females and 11 males) in the study ranged in age from 37-89 years old and had lived with T2DM from less than one year to greater than 25 years. Facilitators for self-management in men were regular appointments with health care providers, a positive outlook regarding living with T2DM, making health a priority, and maintaining independence in T2DM self-management. The facilitator for women was acceptance of the diagnosis. Barriers to self-management identified in these women were limited finances, embarrassment related to the regimen (glucose monitoring and insulin injections), negative outlook towards self-management, uncertainty related to the effects of medications, and lack of control with T2DM. Interestingly, men identified a lack of family support related to food preparation as a barrier when independence was a facilitator. Other barriers identified by men were a perceived lack of diabetes knowledge and no time during the workday for self-management, including eating regularly and self-monitoring of blood glucose.

Two comparable studies that used focus groups to explore adherence to dietary recommendations in African American men and women living with T2DM acknowledged the value of eating healthy. Some challenges discussed were the need for ongoing support from family, friends, and health care providers, difficulty applying information from diabetes education at home, and struggling with changing diet. Decreased understanding of how food choices impact glycemic control and the cost of healthier food choices were also included (Lee et al., 2016, 2019; Murrock et al., 2013).

Using semi-structured interviews, Bonner et al. (2017) investigated foot care knowledge in African Americans with T2DM (*n*=13) and their perception of the potential for diabetes-related foot complications. Findings indicated participants were not knowledgeable about basic diabetes foot care and the risk of lower extremity complications resulting from poor glycemic control and recommended including a detailed foot care education tool in diabetes self-management education (Bonner et al., 2017).

In a study with African American and Latino men with T2DM exploring psychosocial factors in self-management and health care use, structural barriers (cost of health care, finances, and work) were identified. Participants shared concerns about accumulating medical bills, not seeking medical care, and the cost of diabetes medications and supplies. These structural barriers affected their engagement in diabetes self-management (Hawkins et al., 2015).

Identifying the Self-Care of Diabetes

The findings of one study indicated advice on diabetes self-care from healthcare providers could play a key role in whether individuals carry out self-care activities (Miller et al., 2016). Ninety-six African American women participated in this study, with a mean age of 53. Most participants had health insurance coverage, but only about half reported attending any formal diabetes education classes. One finding demonstrated an association between not receiving self-care advice and engagement in diabetes self-care, specifically physical activity (Miller et al., 2016).

Using national survey data, Chen et al. (2014) conducted an observational study on US adults from 2001 to 2010. Non-Hispanic Black adults were 15% of the survey (*n*= 355,620). Findings indicated that respondents aged 18-44 were less likely to receive diabetes care. Possible barriers were other daily life demands, self-care of diabetes not viewed as a priority, and current disease severity. Regarding diabetes self-care, non-Hispanic Black adults had less engagement in exercise and obtaining flu shots, but performed foot checks, received HbA1c tests, and checked blood glucose (Chen et al., 2014).

Bonner et al. (2019) conducted a pilot study examining the association between basic and extended foot care knowledge and practices among African Americans with T2DM (*n*=95). Participants completed a foot care knowledge questionnaire along with health descriptors and demographics. Findings showed participants' extended foot care knowledge was less than basic foot knowledge and was influenced by insurance coverage which could be protective in preventing lower extremity disease complications. There were also differences in how this population translated foot care knowledge into the performance of foot care (Bonner et al., 2019). This study focused on the diabetes self-care behaviors of foot care, and other aspects of diabetes self-care were not measured.

The association of the practice of diabetes self-care between and among other variables such as income, health insurance education level, diabetes distress, time management, gender, and healthcare provider advice was examined in several studies (Gumbs, 2020; Hernandez et al., 2014; Miller et al., 2016; Rahim-Williams, 2011; Summers-Gibson, 2021). These studies found that a lack of health insurance influenced diabetes self-care. Lack of health insurance affected access to a health care provider for preventative and maintenance services (HbA1c tests, lab monitoring, dilated eye exams, and provider foot exams) and referrals to diabetes education and counseling about diabetes self-care (Gumbs, 2020; Miller et al., 2016).

Measuring Self-Care of Diabetes

The instruments used in studies to measure self-care of diabetes behaviors vary in the concepts identified and ultimately measured. Instruments measuring comprehensive diabetes self-care behavior and the individual’s decision-making process are limited. The instrument selected for this study was the Self-Care of Diabetes Inventory (SCODI). SCODI is a self-reported inventory guided by the middle-range theory, the *Theory of Self-Care of Chronic Illness*, measuring the concepts of self-care of diabetes (Ausili et al., 2017; Riegel et al., 2012). The theoretical concepts are self-care maintenance, self-care monitoring, and self-care management. The SCODI is a new instrument by Ausili, who collaborated with Riegel in its development. Multiple psychometric studies with SCODI have been performed, and the instrument has been translated into other languages (Ebadi et al., 2019; Kong & Cho, 2021; Uchmanowicz et al., 2020). Studies utilizing SCODI have evaluated how self-care maintenance, self-care monitoring, and self-care management affect HbA1c and gender differences in self-care behaviors of adults with T2DM. The measure of self-care confidence was also evaluated as an influencing factor for the concepts. A generalizability study conducted with participants in Italy and the United States for using SCODI demonstrated support for its use in other countries for diabetes research to advance knowledge in the self-care of diabetes (Ausili et al., 2020). The use of SCODI provides a framework grounded in theory to measure self-care of diabetes; and develop and assess self-care interventions tailored for specific populations (Jaarsma et al., 2020).

Diabetes Distress

The daily attention needed to manage type 2 diabetes can result in fear, worry, anger, and uncertainty, described as emotional distress. This emotional response to living with diabetes led to the introduction of the concept of diabetes distress by psychologists and psychiatrists from Joslin Diabetes Center in 1995 (Dennick et al., 2017; Polonsky et al., 1995, 2005; Skinner et al., 2019). Diabetes distress is the concern individuals living with diabetes experience regarding managing diabetes over time (Diabetes Distress Assessment & Resource Center, n.d.). Diabetes distress can be misinterpreted as depression or anxiety, but it is not a psychiatric diagnosis (Fisher et al., 2010, 2019; Rariden, 2019; Skinner et al., 2019). Fisher et al. (2014) shed light on understanding two components of diabetes distress: content and severity. Content is the day-to-day diabetes self-care activities, presence or absence of social support, complications, and feeling overburdened (Fisher et al., 2014; Rariden, 2019). Severity is the degree of diabetes distress ranging from little to severe (Fisher et al., 2014). The significance of diabetes distress in self-management is growing with recommendations to include assessing, intervening, and evaluating diabetes distress as part of routine diabetes care (American Diabetes Association Professional Practice Committee, 2021c; Association of Diabetes Care and Education Specialists, 2021). Diabetes distress is an expected emotional response to living with the day-to-day self-care behaviors needed for the self-management of T2DM (Fisher et al., 2010, 2019; Polonsky et al., 1995, 2005). Self-care of diabetes requires daily engagement in multiple activities to achieve and maintain a glycemic target of HbA1c of <7% (American Diabetes Association Professional Practice Committee, 2021d).

Exploring Diabetes Distress

Diabetes distress is associated with decreased engagement in self-care of diabetes behaviors leading to poorer glycemic control and an increased risk of diabetes-related complications. Mental health disorders, depression, and anxiety can all impact self-care of diabetes, but diabetic distress is expected; therefore, regular diabetes distress screening and other mental health screenings are recommended (Fisher et al., 2008, 2010).

A study with African American participants exploring psychosocial factors influencing and impacting diabetes self-management reported several diabetes self-care behaviors that could increase the risk of diabetes distress (Bhattacharya, 2012b). While not explicitly identified as diabetes distress, participants shared increased stress related to following dietary guidelines and food preparation. They were told their traditional/cultural foods were not good for them and were uncertain if they could participate in social gatherings due to dietary restrictions. Physical activity recommendations produced a feeling of being overwhelmed in individuals because they could not incorporate exercise into their daily routine, did not have a safe place to exercise, or feared injury. Words used to describe participants' feelings about the long-term use of medication, constant monitoring, and uncertainty regarding the ability to incorporate the needed lifestyle changes were worried, doubtful, and fearful (Bhattacharya, 2012b).

Identifying Diabetes Distress

Studies indicate a relationship between the duration of diabetes, family history of diabetes, treatment regimen, relationship with the health care provider, and diabetes distress (Hernandez et al., 2020; Parsa et al., 2019). One study identified clinical determinants such as elevated HbA1c, body mass index (BMI), and triglycerides that can predict diabetes distress (Parsa et al., 2019). Another study examining diabetes distress and social support in adults with T2DM found that participants with low social support are more likely to experience severe diabetes distress associated with inadequate diabetes self-management (Presley et al., 2021). Participants desired more emphasis on how they coped with diabetes versus a review of lab results during encounters with healthcare providers (Hernandez et al., 2020).

In a mixed methods study by Hood et al. (2018), 155 urban-dwelling African Americans were surveyed using the Diabetes Distress Scale. Findings indicated that the participants had moderate levels of regimen distress and emotional burden, while the interpersonal and physician distress were low. Results from the focus groups found that participants wanted healthcare professionals to understand the impact of diabetes on mental health and requested culturally appropriate resources be available.

Summers-Gibson (2021) examined the relationship between and among diabetes self-care, diabetes distress, and diabetes time management. Findings suggested diabetes time management influenced the practice of diabetes self-care more than diabetes distress. Although time management was identified as more of a predictor than diabetes distress, the participants (*n*=188) had a moderate amount of diabetes distress. African American women were only 8.5% of the study.

Hernandez et al. (2014) examined correlates of self-care in low-income African American (*n*=133) and Latino (*n*=117) participants with T2DM (*n*=250) who were recruited from federally qualified health clinics. The Summary of Diabetes Self-Care Activities instrument measured general diet, specific diet, physical activity, blood glucose monitoring, and foot care. Participants provided a self-report of how times they performed self-care behaviors in the last seven days. The specific diet asked how frequently an individual ate fruits, vegetables, or high-fat foods (Toobert et al., 2000). Additional variables examined were diabetes distress, self-efficacy, age, gender, income, insurance status, and education level. Diabetes distress was measured using the Diabetes Distress Scale 17, and the Diabetes Empowerment Scale-short form was used to measure diabetes-related psychosocial self-efficacy. A strength of this study was the performance of a separate statistical analysis to better understand the findings in each population within the sample (Hernandez et al., 2014). African Americans in this study had poorer glycemic control, more insulin use, and more health insurance than their Latino counterparts. Findings indicated African American participants had moderate diabetes distress. The regularly performed self-care behaviors were foot care and blood glucose testing, followed by adhering to the general/specific diet, and the lowest was physical activity. Diabetes distress had a strong association with diabetes self-care behaviors. Lower levels of diabetes distress increased adherence to recommended dietary guidelines, blood glucose testing, and foot care. Higher diabetes distress decreased engagement with physical activity (Hernandez et al., 2014).

Studies examining the presence of diabetes distress revealed that participants had moderate to severe levels of distress measured by the Diabetes Distress Scale. Emotional burden and regimen distress subscales had higher scores. This finding coincided with participant statements in qualitative studies about the stress of day-to-day management and the uncertainty that lifestyle changes or daily medication use would help (Bhattacharya, 2012b; Helgeson et al., 2020; Hood et al., 2018; Presley et al., 2021). More research examining diabetes distress in non-Hispanic Black adults with T2DM was recommended.

Linking Self-Care of Diabetes and Diabetes Distress

Studies measuring both concepts suggest higher diabetes distress influences self-care of diabetes, but the magnitude and strength are unclear. Hood et al. (2018) conducted a mixed methods study to understand diabetes-related distress characteristics and psychosocial support preferences in urban African American adults (*n*= 155; 67 males and 88 females). The Summary of Self-Care of Diabetes Activities measured self-care, but the elements assessed were not clearly stated. In regards to diabetes self-care, the sample was scored moderately. The Diabetes Distress Scale 17 measured diabetes distress (Polonsky et al., 2005). The total diabetes distress score demonstrated the participants had a moderate amount of diabetes distress with the highest scores in subscales of emotional burden and regimen distress. In the qualitative arm of this study, focus groups described emotional stressors and feeling overwhelmed with day-to-day management, i.e., emotional burden and regimen distress (Hood et al., 2018). Both concepts were measured, but the relationship between self-care of diabetes and diabetes distress was not examined.

Helgeson et al. (2021) examined the racial difference in psychological behavior and physical health over six months among individuals diagnosed with type 2 diabetes in a community sample (*n*=193; 45% African American). Diabetes distress, self-care, and HbA1c were measured at time 1 and six months later at time 2. The Summary of Self-care of Diabetes

Activities was used to measure self-care. Self-care behaviors of diet, physical activity, and medication adherence were identified as challenging. African American participants had increased calorie intake of carbohydrates and proteins, and Black women had less medication adherence at time 2. HbA1c values were higher in Black participants with no change from time 1 to time 2 but significantly higher than in White participants. Diabetes Distress Scale 17 was used to measure diabetes distress. African American female participants had moderate diabetes distress with no change from time 1 to time 2. The relationship between self-care of diabetes and diabetes distress was not examined at time 1 or 2.

Hernandez et al. (2014) examined the correlates of self-care in low-income African Americans and Latino patients with diabetes (*n*= 250; 53% African American; ages 25-86 years old). African American participants had higher HbA1c levels, greater education levels, and more insulin use. Diabetes distress was negatively correlated with engagement with diet behaviors, physical activity, blood glucose monitoring, and foot care. Increased diabetes distress suggests less engagement in self-care behaviors.

The occurrence of diabetes distress ranging from moderate to severe is prevalent in this population. It has been associated with the decreased performance of self-care of diabetes behaviors highlighted in these studies. The ongoing measurement of self-care of diabetes and diabetes distress and the examination of the relationship between these variables in this population could lead to more targeted interventions to improve engagement in self-care of diabetes behaviors and lower diabetes distress. Further self-care research is recommended to determine the influence on healthcare outcomes.

Summary of Review of Literature

Much of the literature reviewed highlighted the challenges associated with the performance of self-care of diabetes and diabetes distress in non-Hispanic Black adults with T2DM. Lack of health insurance affects access to diabetes care, formal diabetes education, and health care provider support or advice related to the self-care of diabetes. Individuals without health care coverage engaged in foot care behaviors and participated in health-promoting diabetes self-care behaviors (eye exams, provider foot exams, HbA1c testing), took medications, and checked blood glucose less often due to costs (Bonner et al., 2017, 2019; Chlebowy et al., 2013; Gumbs, 2020). Lack of diabetes knowledge about the disease and understanding of the chronicity of diabetes was often influenced by not having health insurance and limited access to formal diabetes education (Murrock et al., 2013; Onwudiwe et al., 2011). The dietary and physical activity recommendations were perceived as unreasonable and often identified as challenging diabetes self-care behaviors to initiate and maintain over time (Bhattacharya, 2012a, Miller et al., 2016; Sherman et al., 2014).

The literature review describes the current knowledge about self-care of diabetes and diabetes distress in non-Hispanic Black adults. The reported emotional stress associated with living with diabetes highlights the impact of the daily demands contributing to feeling overwhelmed. The themes that emerged through focus groups and semi-structured interviews alluded to participants not believing they could incorporate the recommended lifestyle changes.

The *Theory of Self-Care of Chronic Illness* guided this study in assessing the self-care of diabetes in non-Hispanic Black adults. Self-care is a process by which individuals perform specific behaviors to manage a chronic illness such as diabetes independently and in consultation with healthcare providers (Riegel et al., 2012, 2018). Engagement in the self-care of diabetes is critical for individuals living with T2DM (Rahim-Williams, 2011). The theory concepts (self-care maintenance, self-care monitoring, and self-care management) build upon each other and include problem-solving and decision-making.

Recognizing that diabetes distress can impact one’s ability to manage self-care activities, the concept of diabetes distress should be considered when studying self-care behaviors. The relationship between self-care of diabetes and diabetes distress in non-Hispanic Blacks has been demonstrated in a few studies thus far in the literature. Additional research is needed to understand better the self-care behaviors of non-Hispanic Blacks living with T2DM and its relationship with diabetes distress.

CHAPTER III: METHODOLOGY

Design

A cross-sectional correlational design was conducted to examine relationships between and among the concepts of self-care diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes stress in non-Hispanic Black adults ages 18-64 years old living with T2DM in North Carolina. This study design collected data at a set point in time versus longitudinally. It was appropriate for the study, allowing the participants to report their self-care of diabetes behaviors and diabetes distress (Aggarwal & Ranganathan, 2019; Creswell & Creswell, 2018; Cummings & Sanders, 2019; Polit & Beck, 2017, 2017; Siedlecki, 2020). Participants were asked questions that prompted reflection on their self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress.

Research Questions

1a. What is the level of self-care maintenance in non-Hispanic Black adults living with T2DM as measured by the Self-Care of Diabetes Inventory (SCODI)?

1b. What is the level of self-care monitoring in non-Hispanic Black adults living with T2DM as measured by the Self-Care of Diabetes Inventory (SCODI)?

1c. What is the level of self-care management in non-Hispanic Black adults living with T2DM as measured by the Self-Care of Diabetes Inventory (SCODI)?

2. What is the level of overall diabetes distress and its subscales of emotional burden, regimen distress, interpersonal distress, and physician distress in non-Hispanic Black adults living with T2DM as measured by the Diabetes Distress Scale 17 (DDS17)?

3a. Is diabetes distress associated with adequate self-care maintenance as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

3b. Is diabetes distress associated with adequate self-care monitoring as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

3c. Is diabetes distress associated with adequate self-care management as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

4a. Is emotional burden, physician distress, regimen distress, and interpersonal distress associated with adequate self-care maintenance as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

4b. Is emotional burden, physician distress, regimen distress, and interpersonal distress associated with adequate self-care monitoring as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

4c. Is emotional burden, physician distress, regimen distress, and interpersonal distress associated with adequate self-care management as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

Population and Setting

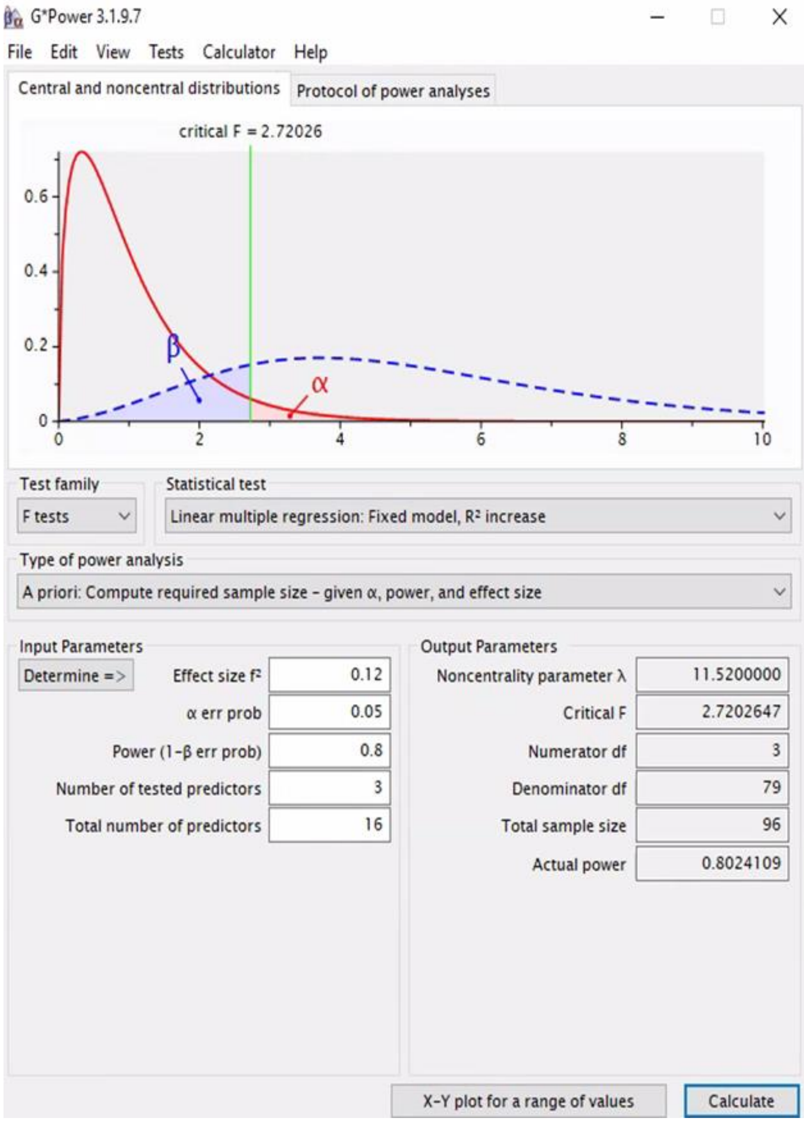
The study was conducted in North Carolina, which ranks number eight among the ten states with the highest non-Hispanic Black population (World Population Review, 2022). Non-Hispanic Blacks are 22% of the state's population (United Health Foundation, n.d.-b; World Population Review, 2022). In North Carolina, 12.4% of the adult population is diagnosed with diabetes, an estimated 72,032 adults (ADA, 2022). According to the 2021 United Health Foundation Report using 2020 CDC data, the prevalence of diabetes in Black North Carolinians was about 17% (United Health Foundation, n.d.-a). In 2017, North Carolina's total direct medical expenditures for diagnosed diabetes were $7.7 billion, and indirect costs from lost productivity due to diabetes were $2.9 billion (ADA, 2022). As a clinician, non-Hispanic Black adults were selected due to the prevalence of T2DM in the population, which supported obtaining a sample size needed for the study.

Sample

Participants were recruited from community-based settings using convenience sampling. The criteria for inclusion included (a) self-identification as non-Hispanic Black, African American, or Black adult, (b) 18-64 years old, (c) diagnosed with T2DM by a health care provider, (d) able to speak English fluently, (e) able to read and understand English, (f) and currently living in North Carolina. Exclusion criteria for this study were (a) pregnancy, (b) diagnosis of type 1 diabetes, gestational diabetes, prediabetes, or other forms of diabetes, (c) self-reported history of memory or cognitive problems, (d) on hemodialysis, received a kidney transplant or had lower extremity amputation related to diabetes complications.

A priori power analysis was conducted using G*Power statistical power analysis 3.0 version to determine the sample size and statistical power needed to strengthen the study. A priori power analysis was performed using F tests with a statistical test of linear multiple regression: fixed model, with a significance level of .05 (two-tailed), 80% power, and an estimated effect size of $R^2 = 0.12$ to calculate the required sample size. Using the G*Power, the three predictor variables (self-care maintenance, self-care monitoring, and self-care management) and 13 independent variables indicated that 96 participants would be required. A target sample size of 110 was established, which was 10% above the estimate (Faul et al., 2007) (see Figure 1).

Figure 1. G* a Priori Power Analysis



Test family: F tests

Statistical test: Linear multiple regression: Fixed model, R^2 increase

Type of power analysis: A priori: Compute required sample size – given α, power, and effect size

Input Parameters

Effect size f^2: 0.12
α err prob: 0.05
Power (1-β err prob): 0.8
Number of tested predictors: 3
Total number of predictors: 16

Output Parameters

Noncentrality parameter λ: 11.5200000
Critical F: 2.7202647
Numerator df: 3
Denominator df: 79
Total sample size: 96
Actual power: 0.8024109

Note. G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences (Faul et al., 2007)

Recruitment

Historically, the recruitment of non-Hispanic Black adults has been challenging due to the history of mistrust related to medical research (Kennedy-Malone et al., 2022; Randolph et al., 2018; Sherman et al., 2017; Vaughan et al., 2022; Williams et al., 2011). The researcher consulted with colleagues, peers, and friends concerning the potential recruitment sites. Once potential sites were identified, the researcher sent an inquiry email or called the contact person. The email included an introduction and provided a brief overview of the study. Further information was provided when potential sites expressed interest. The information included a request for a letter of support for submission to the UNCG Institutional Review Board (IRB), the explanation that active recruitment would only occur after approval from the IRB was received, the role of participants, and the option to participate in a random drawing done at the end of the survey. Letters of support were submitted with the IRB application.

Recruitment strategies aimed intentionally to engage individuals from all socioeconomic statuses and backgrounds. Participants were recruited from community-based settings such as faith-based institutions, social organizations (fraternities and sororities), local business establishments (hair salon and barbershop), and ambulatory medical practices. The researcher's contact information was on all forms of communication, and a TracFone was purchased for use during the study.

The researcher created templates for communication with recruitment sites during the inquiry process and throughout the study. Recruitment materials such as the research flyer (See Appendix A) and in-person, virtual, and social media scripts were also developed. Email distribution and letter of support templates were also created. Recruitment materials were submitted with the IRB application.

After receiving study approval from the University of North Carolina at Greensboro Institutional Review Board (IRB), the recruitment phase began. The following recruitment strategies were implemented: flyer distribution, three in-person presentations, a video message embedded in a PowerPoint was used by recruitment sites, virtual platform presentations via

Zoom for two recruitment sites, participation in a recruitment site Bible study, participation in a recruitment site’s state conference and social media postings (FaceBook and Instagram). Flyers were distributed with a QR code to scan and take participants directly to the survey via email and postings on social media (FaceBook and Instagram). An email distribution template with a URL link was sent to the recruitment site contact person. The researcher posted the study information and flyer on social media (FaceBook and Instagram). The researcher recorded and posted the in-person announcements on social media with multiple shares and views. The researcher hosted three Zoom meetings to engage potential participants after recruitment sites distributed recruitment materials. The notice about the Zoom meetings was posted on the FaceBook Group page of one recruitment site, which was public, so there was an opportunity for others to attend.

Recruitment Connections

Participants were recruited from community-based settings. The researcher networked with nurse practitioners who owned their practices in the NC Triangle and Triad areas to be recruitment sites. The nurse practitioner colleagues also shared access to their social networks such as professional organizations, fraternities, and sororities.

The researcher had previous relationships with two faith-based organizations and was referred by colleagues and friends to other faith-based organizations. A friend connected the researcher with his fraternity's North Carolina Director of Social Action, who promotes activities focused on the health and wellness of their membership. The fraternity posted the study information and video message on their group's FaceBook. Two sororities were identified through peers and colleagues. The researcher was a hair salon patron, and the barbershop owner was a friend of a friend. Family and friends shared about the research study by sharing the researcher's social media posts on their social media and by word of mouth.

The in-person recruitment efforts provided the opportunity for face-to-face interaction with potential participants. The researcher was able to answer additional questions and clarify eligibility criteria. Scanning the QR code was done without difficulty, and participants often sat and completed the survey. Despite the verbal overview and the study description on the flyer, a few individuals scanned the QR code and did not move past the screening code. An individual commented, "I received the message that I did not qualify for the study." The receipt of the standardized message validated the features added to the survey screened appropriately for eligible participants. During virtual recruitment efforts via Zoom meetings, participants could scan the QR on the screen or click on the link placed in the chat. Some participants stayed in the Zoom meeting, completed the survey, and needed minimal assistance from the researcher. In-person and virtual recruitment efforts provided the researcher more time to engage and inform individuals about the role of nursing research.

During a conservation fraternity recruitment site about the details related to a presentation about the research study at their state conference, they shared the research study's social media reach. FaceBook engagement reached over 1K, video messages had over 3.5K views, two of the GroupMe groups reached 662 members, the email distribution was 700, and the Instagram story had 100 views. There was likely some overlap, but the message was circulated multiple times within the membership.

Recruitment sites selected the recruitment strategies they felt worked best for their organization. The organizations circulated study information through their meetings and social media. The survey collected no personal information, and the researcher sent no follow-up emails to complete the survey.

Instrumentation

A questionnaire and two instruments were used collect for data collection: (a) the Socio-demographic and Clinical Characteristics Questionnaire, (b) the Self-care of Diabetes Inventory (SCODI), and (c) Diabetes Distress Scale 17 (DDS17). The questionnaire and two instruments were administered via an online survey. A paper survey was an option, but there were no requests for the in-person paper survey. The initial estimated completion time for the study survey was 45 minutes.

Socio-Demographic and Clinical Characteristics Questionnaire

The investigator-designed questionnaire consisted of twenty-eight questions to collect socio-demographic and clinical characteristics data. Participant responses described the sample. The following socio-demographic characteristics were collected: age, gender, educational level, marital status, health insurance, income, and use of online resources for diabetes information. The following clinical characteristics were collected: the age when diagnosed by a health care provider with T2DM, the number of years diagnosed with T2DM by a health care provider, frequency of office visits with a primary care provider or endocrinologist, participation in formal diabetes education, self-reported last HbA1C, knowledge about whether HbA1C, BMI or blood pressure were at recommended levels, medication use for diabetes, comorbidities, presence of diabetes-related foot problems, ulcers or infections, family history of T2DM or gestational diabetes, presence of support system, and how did the individual learn about the research study. The socio-demographic and clinical characteristics were consistent with data obtained in diabetes research studies, including psychometric studies for instruments used (Ausili et al., 2017; Hernandez et al., 2014; Polonsky et al., 2005; Summers-Gibson, 2021). The dissertation committee reviewed the investigator-developed questionnaire. The dissertation committee consisted of nurse researchers, a nurse practitioner, a public health professional, and a statistician who provided consensus and reviewed the investigator-developed questionnaire for content validity.

Self-Care of Diabetes Inventory

The Self-Care of Diabetes Inventory (SCODI) is a 40-item self-reported inventory (See Appendix C). The middle range theory, the *Theory Self-Care of Chronic Illness,* guided instrument development (Ausili et al., 2017; Riegel et al., 2012). SCODI measures self-care behaviors individuals living with diabetes perform to maintain health and wellness, monitor diabetes for symptoms of hypoglycemia or hyperglycemia, and the confidence in performing the activities (Ausili et al., 2017; Riegel et al., 2012). The items ask about the self-care of diabetes behaviors of the individual during the past 30 days (Ausili et al., 2017). The instrument consists of five-point Likert-type response options ranging from (1) “never” to (5) “always” for self-care maintenance, self-care monitoring, and self-care management; (0) “I didn’t recognize symptoms” to (5) “very quickly” for two items of self-care monitoring; and (1) “not confident at all” to (5) “extremely confident” for self-care confidence. The validation study was conducted with Italian adults with type 1 and type 2 diabetes (N=200). The concepts of self-care maintenance (12 items), self-care monitoring (8 items), self-care management (8 items), and a measure of self-care confidence (12 items) were grouped into four scales. Self-care confidence is not a concept of the theory or an element of self-care but is a strong influencing factor in self-care maintenance, self-care monitoring, and self-care management (Ausili et al., 2017).

Self-Care of Diabetes Inventory (SCODI) was administered via Qualtrics, an online survey software for this research study. It was also available as a paper survey that followed the same format as the online survey if requested. SCODI has been translated into fourteen languages. It can be used without any charge. A user agreement for the use of SCODI was submitted and signed by the developer (see Appendix B). The researcher was advised that the instrument could not be revised without permission, must be cited appropriately in publications, and could not be placed in any publications (Self-Care Measures, n.d.). The amount of time needed to complete the paper form of the instrument was not included in the psychometric studies or other studies using the instrument.

There is no summative score with SCODI, but each scale is scored individually. A score greater than 70 is considered adequate self-care, and less than 70 is considered inadequate self-care (Ausili et al., 2018). The instructions for scoring the instruments are on the website (Self-Care Measures, n.d.). The scale score is standardized: “1) determine the maximum possible scale score, 2) subtract the number of items from the possible score, and 3) divide 100 by that result to identify a constant for that scale. To score the scale, sum item responses, subtract the number of items answered, and multiply by the constant” (Self-Care Measures, n.d.).

SCODI demonstrated content validity, construct validity, and reliability in measuring self-care maintenance, self-care monitoring, and self-care management. The scales are multi-dimensional. Cronbach’s alpha reported overall reliability for each scale, and the global reliability index for multi-dimensional scales reported for scale dimensions. Cronbach’s α for overall self-care maintenance was .55, and the global reliability index for multi-dimensional scales was .81. Cronbach’s α for overall self-care monitoring was .65, and the global reliability index for multi-dimensional scales was .84. Cronbach’s α for overall self-care management was .77, and the global reliability index for multi-dimensional scales was .86. Cronbach’s α for overall self-care confidence was .90, and the global reliability index for multi-dimensional scales was .89. In the study, self-care maintenance, self-care monitoring, and self-care management were operationalized using their scores in regression models.

Diabetes Distress Scale 17

The Diabetes Scale 17 (DDS17) is a self-reported 17-item questionnaire developed to screen individuals for overall diabetes-related distress and identify specific areas of stress (emotional burden, regimen distress, interpersonal distress, and physician distress; see Appendix C). The items ask the degree to which each item has distressed or bothered the individual during the past month (Fisher et al., 2012; Polonsky et al., 2005). The instrument consists of a six-point Likert scale, scoring each item from (1) “not a problem” to (6) “a very serious problem” for each item. The validation study was conducted with individuals with type 1 and type 2 diabetes (*N*=683).

The total Diabetes Distress Score17 (DDS17) is obtained by averaging the responses across items 1-17. Instructions for scoring DDS17 were located on the website (Diabetes Distress Assessment and Resource Center, 2017). Subscales (emotional burden, regimen distress, interpersonal distress, and physician distress) are scored by averaging. The emotional burden is the average of five items (1, 4, 7, 10, 14); regimen distress is the average of five items (6, 8, 3, 12, 16); interpersonal distress is the average of three items (9, 13, 17), and physician distress is the average of four items (2, 5, 11, 15). The explanation of average scores is as follows: <2.0 reflects little or no distress; 2.0–2.9 reflects moderate distress; and ≥3 reflects high distress (Fisher et al., 2012). The total score gives the overall level of diabetes distress, and the subscales can allow a more focused look at areas of concern.

DDS17 demonstrated convergent validity and was positively associated with depressive symptomatology measured with the Center for Epidemiological Studies Depression Scale

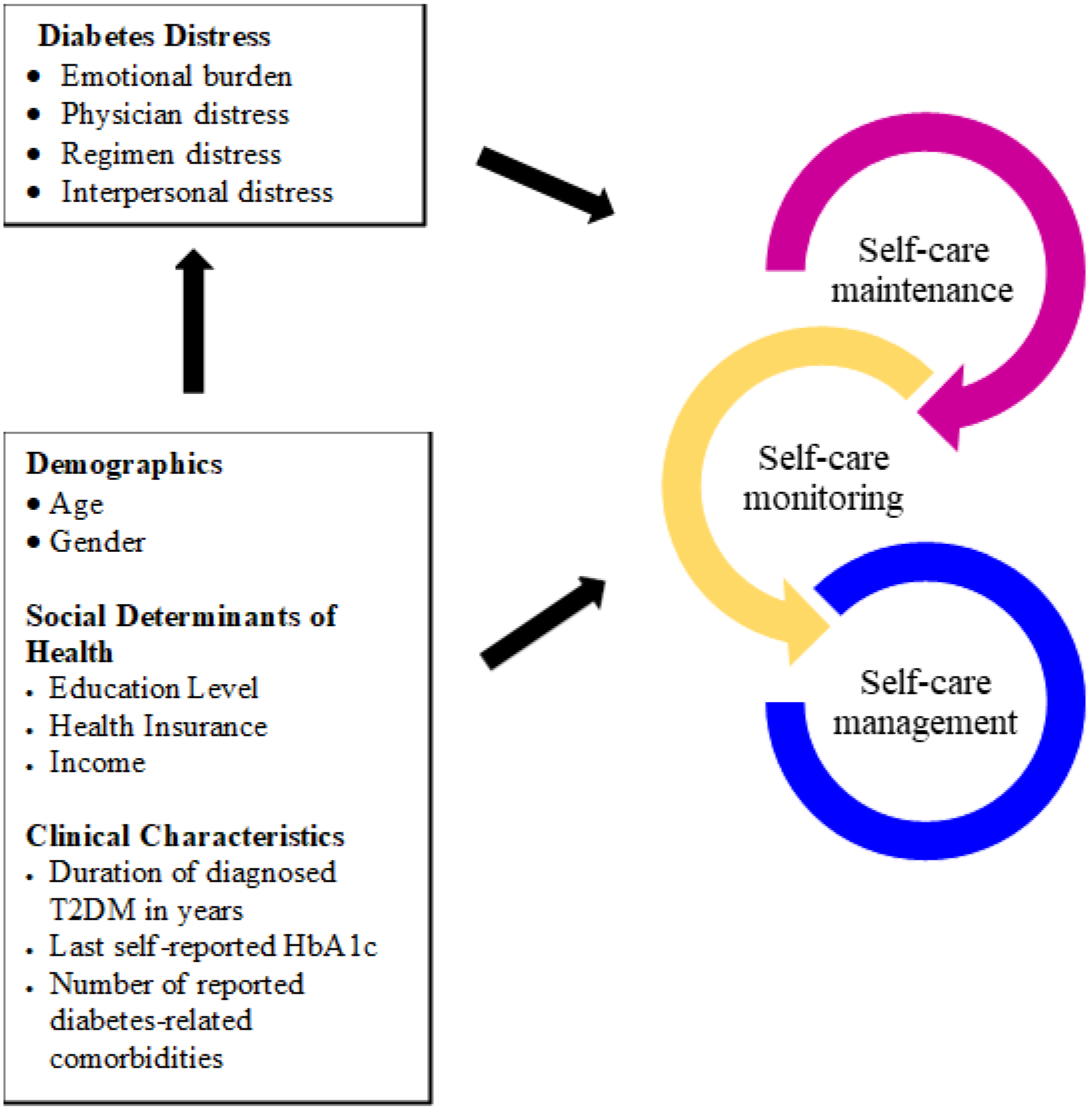
(Polonsky et al., 2005). Cronbach's α for the 17-item scale (total diabetes distress) = .93; emotional burden =.88; regimen distress =.90; interpersonal distress =.88, and physician distress = .88. DDS17 has been translated into thirty-seven languages. The instrument is available at no charge for clinical use and research to non-profit institutions in a paper and online version (Appendix B). The time to complete the paper form is 10 minutes (Behavioral Diabetes Institute, n.d.). DDS17 was added to the online survey in Qualtrics. The study operationalized diabetes distress and its subscales (emotional burden, regimen distress, interpersonal distress, and physician distress) using the total diabetes distress score and the subscale scores in regression models.

The psychometric studies for the Self-care of Diabetes Inventory and Diabetes Distress Scale 17 supported their use in this study. The socio-demographic questionnaire collected participant characteristics. The data collected with the online survey allowed participants to complete the questionnaire and instruments at their own pace.

Conceptual and Operational Definitions of Variables

The conceptual and operational definitions for this study were derived from the *Theory of Self-Care of Chronic Illness*, diabetes distress literature, demographic, social determinants of health (SDOH), and clinical characteristics used in diabetes research studies (Ausili et al., 2018; Polonsky et al., 2005; Riegel et al., 2012, 2018, 2019; World Health Organization, n.d.). The variables measured in this study were self-care maintenance, self-care monitoring, self-care management, self-care confidence, diabetes distress (emotional burden, regimen distress, interpersonal distress, and physician distress), socio-demographic characteristics, social determinants of health, and clinical characteristics, as shown in Figure 2.

Figure 2. Self-Care of Diabetes and Independent Variables for the Study



Note. Adapted from the *Theory of Self-Care of Chronic Illness* (Riegel, 2012)

1. Self-care of Diabetes: Behaviors of individuals living with diabetes to maintain or improve their health (Riegel et al., 2012, 2018). Self-care is multi-dimensional, and each scale is measured individually. An overall score for self-care is not calculated. A higher score indicates better self-care (Ausili et al., 2017).
2. Self-care maintenance: An individual’s daily self-care of diabetes behaviors or activities to maintain or improve health and physical and mental well-being (Riegel

et al., 2012, 2018). For this study, self-care maintenance was operationalized as the Self-Care of Diabetes Inventory (SCODI) score with items 1-12 (Ausili et al., 2017).

3. Self-care monitoring: An individual's ability to be in tune with signs and symptoms related to diabetes (Riegel et al., 2012, 2018). For this study, self-care monitoring was operationalized as the SCODI score with items 13-20 (Ausili et al., 2017).
4. Self-care management: An individual's response to observed changes leads to problem-solving or decision-making related to diabetes (Riegel et al., 2012, 2018). For this study, self-care management was operationalized as the Self-care of Diabetes Inventory (SCODI) score with items 21-28 (Ausili et al., 2017).
5. Self-care confidence: An individual's confidence in their ability to carry out self-care of diabetes behaviors (Riegel et al., 2012, 2018). For this study, self-care confidence was operationalized as the SCODI score with items 30-40 (Ausili et al., 2017).
6. Diabetes distress: An expected emotional response to having diabetes (Fisher et al., 2012; Polonsky et al., 2005). For this study, diabetes distress was operationalized as the total score on the Diabetes Distress Scale 17 (DDS17) from all items (Polonsky et al., 2005).
7. Emotional burden (EB): The level at which an individual feels swamped with managing diabetes every day (Polonsky et al., 2005). For this study, the emotional burden was operationalized as the DDS17 emotional burden subscale score with items 1,4,7,10,14 (Polonsky et al., 2005).
8. Physician distress (PD): The level at which an individual living with diabetes does not feel the healthcare provider is supportive in their efforts or concerned about the care received (Polonsky et al., 2005). For this study, physician distress will be

operationalized as the DDS17 physician distress subscale score with items 2, 5, 11, and 15 (Polonsky et al., 2005).

9. Regimen distress (RD): The level at which an individual does not feel like they are managing diabetes well (Polonsky et al., 2005). For this study, regimen distress was operationalized as the DDS 17 17 regimen distress subscale score with items 6,8,3,12,16 (Polonsky et al., 2005).
10. Interpersonal distress (ID): The level at which an individual living with diabetes feels alone and unsupported by others (Polonsky et al., 2005). For this study, interpersonal distress was operationalized as the DDS17 interpersonal distress subscale score with items 9,13,17 (Polonsky et al., 2005).
11. Demographic characteristics: The characteristics individuals use to describe their social and demographic factors. For this study, socio-demographic characteristics will be operationalized as age and gender from the participant responses on the investigator-designed questionnaire.
12. Social determinants of health (SDOH): The conditions influencing health outcomes not associated with diabetes (World Health Organization, n.d.). For this study, SDOH will be operationalized as health insurance, income, and education level from the participant responses on the investigator-designed questionnaire.
13. Clinical characteristics: Characteristics of individuals that describe self-reported clinical information related to living with diabetes. For this study, clinical characteristics will be operationalized as the duration of diagnosed T2DM in years, the last self-reported HbA1c, and the number of reported diabetes-related

comorbidities from the participant responses on the investigator-designed questionnaire.

Data Collection Procedures

Permissions for instrument use and letters of support were received before recruitment and data collection. Data collection occurred via a confidential online survey.

An online survey was constructed for data collection using Qualtrics. Qualtrics is the online survey software tool that participants used to complete the study's socio-demographic and clinical characteristics questionnaire, SCODI, and DDS 17. The researcher attended basic and intermediate Qualtrics workshops and met with the UNCG Qualtrics specialist to prepare for survey creation with a discussion about using features such as skip, display, and branch logic.

A survey design template from a YouTube Tutorial, Introduction to Making a Qualtrics Survey 2021 (Baker, 2021), was used to organize survey questions and create blocks for entry into Qualtrics. The document provided color codes for actual survey questions, variable names, the logic used in the survey, and code values, which provided a reference before creating the survey in Qualtrics.

Questions were entered into Qualtrics, and various survey features such as skip logic and display logic were used in developing the survey to decide which questions appeared based on responses. Response requirements such as forced response in survey creation were only used to complete screening questions to assess if participants met the study’s eligibility criteria. The request-response option was used for age, age when diagnosed, the number of years living with T2DM, and the last HBA1c, which served as a prompt. Participants could choose not to answer but were still able to continue taking the survey.

Once the initial draft of the survey was created, the researcher met with the UNCG Qualtrics specialist to review the survey, add survey features, and make revisions based on feedback. After additional editing, the researcher consulted with a statistician to check the added survey features and the created survey for the random drawing that linked participants to a completely separate survey from the study's survey. Ongoing consultation included testing the survey, launching and distributing the survey using a QR code, and adding to the flyer and the URL link to the email distribution template. The study and random drawing survey were finalized and ready to be tested (see Appendix C).

Once the final draft was completed, the researcher tested the survey in preview mode and used a test group. A group of eight individuals who were not eligible for the study took the survey to test logic features for screening questions, survey questions, and the random survey, and all the features worked properly. The group of individuals provided feedback stating the questions were easy to understand, the formatting flowed, and the time for completion was shorter than estimated. The time for the group was 15-25 minutes. The survey was launched on July 11, 2022, and closed on September 11, 2022.

Qualtrics collected and stored participant data for exportation to Statistical Package for the Social Sciences (SPSS) version 28 (IBM Corp., Armonk, NY) for statistical analyses. Participant access to a computer, laptop, or mobile device and broadband internet was required to complete the online survey. Participants accessed the study survey via a QR code or a URL link on the flyer, email, or social media sites (FaceBook, Instagram, YouTube, or Twitter).

Online Survey Procedure

The first section of the survey contained the information sheet. It included the purpose of the study, the benefits and risks of participating, the incentive for participation, how confidentiality was maintained, the estimated time for completion of the survey, voluntary participation, and contact information for the researcher and faculty advisor for questions. The researcher's contact information was available on all forms of communication, such as flyers, email, or social media. After reading the information sheet, participants agreed to participate by proceeding to the study's next online survey page.

The next section of the survey consisted of screening questions to determine whether participants met the eligibility criteria for the study. If they met all criteria, they could proceed to the study’s survey questions, including a socio-demographic and clinical characteristic questionnaire, self-care of diabetes inventory, and diabetes distress scale. Individuals not meeting the eligibility criteria received the following standardized message thanking them for their time and willingness to participate in the study. The standardized message was, “Sorry, you did not meet the eligibility criteria for this study. I appreciate your time and willingness to participate in this study.” The online survey option allowed participants to complete it at their convenience and enabled them to return to complete it later if needed.

At the end of the survey, participants who entered the random drawing for ten $25 electronic Amazon gift cards were directed to a separate random drawing online survey from the study data to collect information for a random drawing (email address or phone number). The random drawing information from participants was stored separately from the study data. After the random drawing, the electronic gift cards were sent via email or text to the recipients who won, and the random drawing online survey in Qualtrics was deleted.

Human Subjects Protection

Participants were provided an information sheet that included the purpose of the study, the benefits and risks of participating, the incentive for participation, how confidentiality will be maintained, the estimated time for completion of the survey, and researcher and faculty advisor contact information for questions. Participants were informed that participation was voluntary and could withdraw from the study at any time without penalty. There were minimal physical or emotional risks associated with completing the online or paper survey for the study. Participants could have experienced fatigue when completing the online or paper survey. Participants could decide when to take a break during survey completion and take it at their own pace.

Privacy and Storage of Data

All information collected for the study was kept confidential. All electronic data was stored in Box cloud storage per UNCG ITS recommendations which was more secure than a password-protected computer.

Assumptions for the Study

The assumptions for this study were: (a) the participants answered the survey questions truthfully, (b) all participants may not complete the study, (c) the sample size may not be representative of the general population, (d) the participants have adequate computer literacy and capacity to answer the online survey questions, (e) the respondents to the recruitment flyer are non-Hispanic Black adults ages 18-64 years old, (f) participants were diagnosed with T2DM by a healthcare provider, and (e) participants are residents of North Carolina.

Data Analysis

All survey data from Qualtrics was exported into Statistical Package for Social Sciences (SPSS) version 28 (IBM Corp., Armonk, NY). Frequencies were run on all variables to assess for further missing data and extreme values. Missing values were set to zero for three variables for multi-response questions where participants answered no to the question. Outside of multiple response questions, the missing value percentages ranged from 0-8.4%.

The Self-Care of Diabetes Inventory (SCODI) and Diabetes Distress Scale 17 (DDS17) required the calculation of scores, which were calculated according to the developer's instructions and computed in SPSS. Cronbach's alpha was calculated for SCODI and DDS17 to assess the internal consistency of the instruments in this sample. Cronbach's alpha for both instruments was moderate to high (see Table 1).

Table 1. Internal Reliability of Instruments for Study

Instrument	Cronbach's alpha
Self-care of Diabetes Inventory	
Self-care Maintenance	0.841
Self-care Monitoring	0.769
Self-care Management	0.752
Self-care Confidence	0.878
Overall Diabetes Distress Scale 17 - total	0.956
Emotional Burden subscale	0.860
Regimen Distress subscale	0.878
Interpersonal Distress subscale	0.870
Physician Distress subscale	0.872

Note. Acceptable ranges for Cronbach's alpha are 0.70 to 0.95 (Tavakol & Dennick, 2011)

Descriptive statistics were used to answer research questions 1-2 and illustrated the sample's characteristics and responses to the questionnaire and instruments. Categorical variables were measured using frequencies and percentages. Measures of central tendency, mean, standard deviation, and percentiles were calculated for continuous variables.

Multiple linear regression was used to identify associations with self-care maintenance, self-care monitoring, and self-care management. Confidence intervals of 95% were calculated for each slope coefficient (*b*). A two-sided *p*-value of < 0.05 was considered statistically significant for the regression models.

Research questions 3a-4c initially used multiple linear regression to examine the relationship between self-care maintenance, self-care monitoring, and self-care management and diabetes distress and its subscales (emotional burden, regimen distress, interpersonal distress, and physician distress) as predictors of the self-care concepts. Multiple linear regression models were run with each dependent variable and the independent variables. In Model 1 total diabetes distress score was entered with the dependent variable, self-care maintenance, and in Model 2, the remaining independent variables: demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) were added. Five additional multiple linear regressions were performed following the same procedure for each dependent variable to answer each research question.

Model assumptions were assessed by analyzing residuals. The normality of residuals was assessed using histograms, Q-Q plots, and Shapiro-Wilk test statistic for normality. Variables were normally distributed if the points on the Q-Q plots were reasonably close to the reference line and the Shapiro-Wilk test statistic was nonsignificant (Ghasemi & Zahediasl, 2012; Tabachnick et al., 2019). Linearity and homoscedasticity were assessed using scatterplots for a random pattern around zero on the horizontal line (Jeong & Jung, 2016; Polit, 2010). Durbin-Watson statistic was used to assess for evidence of residual autocorrelation. A value between 1.5-2.5 demonstrates no autocorrelation in the data (Jeong & Jung, 2016). Multicollinearity was assessed by examining the variance inflation factor (VIF). The VIF should be less than 10 (Jeong & Jung, 2016). Outliers for residuals were assessed using Boxplots for mild and extreme outliers (Polit, 2010). All the assumptions for the model were met except for the dependent variable of self-care monitoring which violated the normality assumption and had a significant Shapiro-Wilk

Test. Q-Q Plots had data points away from the reference line. Boxplot identified mild and extreme outliers. Square root transformation was applied to the self-care monitoring dependent variable.

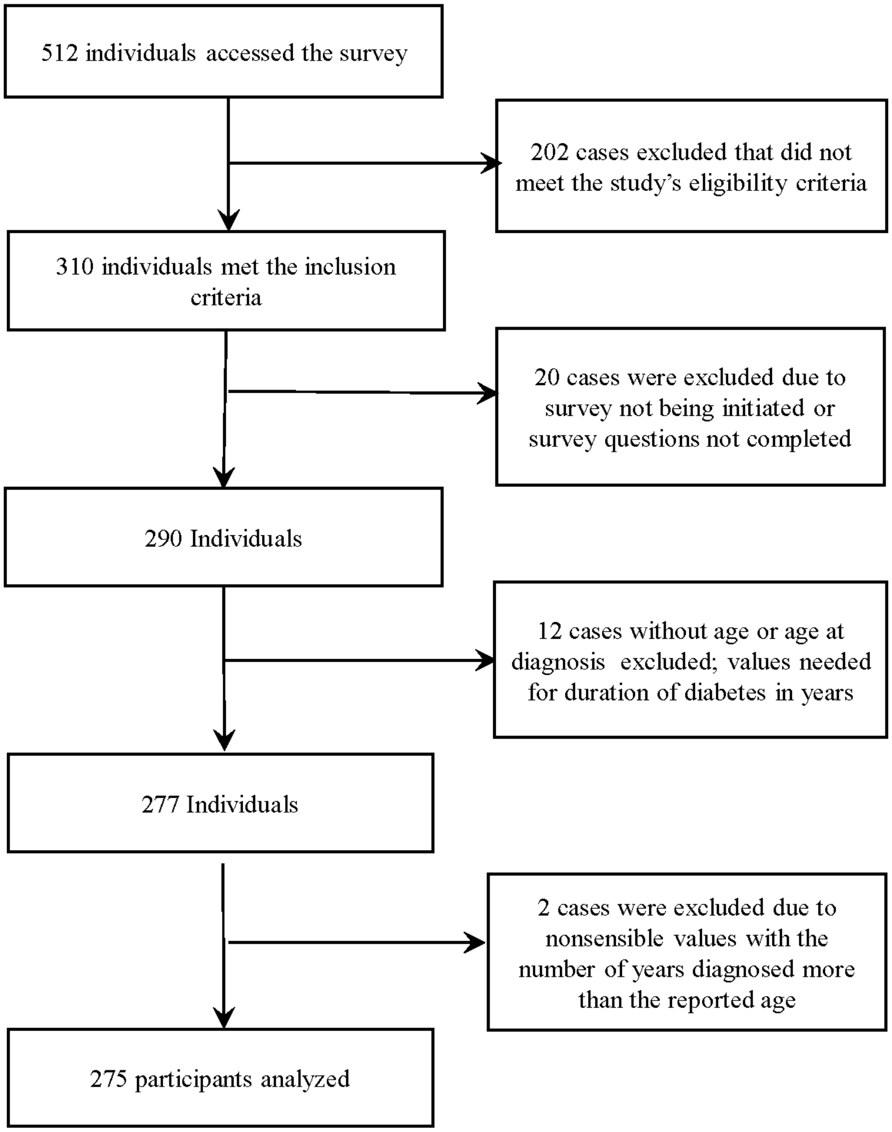
The model was repeated using the transformed variable for self-care monitoring. The normality assumption was no longer violated, and the Shapiro-Wilk Test was nonsignificant, but the sample number decreased from 169 to 94. The cause was unclear of the significant decrease in cases. Therefore, the independent variables were reviewed for coding, and the level of measurement and data screening for missing values was repeated. The education and income variables were ordinal. Education was recoded to a dichotomous variable (high school or less and Associate’s Degree or higher). Income was recoded into a continuous variable and scaled to $25K. Missing were values set to zero for three variables that consisted of multi-response questions where participants answered “no” to the question resulting in missing values. For example, one survey question asked, do you use insulin? The response options were “yes” or “no.” If you answered “yes,” the participant was moved to another question about how they managed it, leaving 101 missing values. The “no” responses were included in these missing values. The missing values for the question were set to zero the missing values decreased to two. The same procedure was carried out on the other two questions, which asked, “do you take medication for T2DM?” and “has your health care provider told you that you have a chronic condition related to T2DM?”

The multiple linear regression was re-run as described above, and model assumptions were assessed by analyzing residuals again. The residuals from these regression models were checked for normality in models 1 and 2, self-care monitoring and self-care management. The normality assumption was violated, and the Shapiro-Wilk Test was significant. Q-Q Plots had data points away from the reference line. Boxplot identified mild and extreme outliers. Square root transformation applied to the self-care monitoring and self-care management dependent variables without change in assumption violations. The data was skewed with extreme outliers. Quantile regression models provide an alternative analysis where the relationship between a set of predictor (independent) variables and specific percentiles (or “quantiles”) of a target (dependent) variable, most often the median” (IBM Documentation, 2022), are modeled. There are no assumptions about the distribution of the dependent variable with no influence of outliers (IBM Documentation, 2022). Both of these assumptions were violated in two of the dependent variables using multiple linear regression.

Median regression was an appropriate alternative regression model to answer research questions 3a-4c to examine the relationship of variables when residuals were non-normally distributed or outliers were present (Lê Cook & Manning, 2013). Luciani et al. (2021) conducted a study using SCODI. The scale scores for self-care maintenance, self-care monitoring, and self-care management were not normally distributed and used quantile regression (Luciani et al., 2021). Median regression was used rather than multiple linear regression to examine the relationship between self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities).

The data were screened to assess how many of the 512 who started the survey met the eligibility criteria (see Figure 3). Of the 512 individuals who accessed the online survey, 310 met the eligibility criteria for the study. Next, the data were screened for initiation of the survey questions and whether the instrument questions were completed. Twenty individuals that did not initiate the survey or complete questions were removed, leaving 290 cases (94% of 310).

Figure 3. Flow Chart of Data Screening Process



Additionally, the twelve cases without age or age at diagnosis were removed because these values were needed to calculate the number of years diagnosed with T2DM. Twelve cases were removed, leaving 277 cases. Finally, two cases were removed due to nonsensible values with the number of years diagnosed more than the reported age. After data screening and cleaning, 275 (95% of 290) participants completed the survey and comprised the analysis sample for reporting findings.

Summary

This cross-sectional correlational study was conducted in non-Hispanic Black adults 18-64 years old diagnosed with type 2 diabetes living in North Carolina. Recruitment occurred in multiple community-based settings. Convenience sampling was used. Participants were given the opportunity to complete a confidential online or paper survey. There were no requests to take the paper version of the survey. The two instruments, the Self-Care of Diabetes Inventory (SCODI) and the Diabetes Distress Scale (DDS17), used to measure the concepts of self-care of diabetes and diabetes distress demonstrated internal consistency reliability in this sample. The SCODI is a newly developed instrument and demonstrated reliability and validity but has limited use in studies, particularly in the United States. In addition to these instruments, an investigator-developed questionnaire to obtain sociodemographic and clinical characteristics was used for data collection. Descriptive statistics and median regression were used to describe the study sample and answer the research questions.

CHAPTER IV: RESULTS

This chapter describes the sample and the results from the analyses to answer the study's research question. The findings from data analysis will be reported with significant results highlighted.

Socio-Demographic Characteristics of the Sample

Participants for this research study were recruited from community-based settings (see Table 2). The most significant percentage of participants learned about the research study through social media (FaceBook and Instagram), followed by professional nursing organizations. The researcher engaged faith-based organizations through in-person or video announcements. Surprisingly, 6.2% indicated they learned about the study through a church.

Table 2. Recruitment Sites (*N* = 275)

How Participants Learned about Research Study	*n*	%
Barbershop	0	0.0
Church	17	6.2
Flyers	2	0.7
Fraternity	10	3.6
Friend	36	13.1
Hair Salon	3	1.1
Health care provider's office	63	22.9
Professional nursing organization	47	17.1
Social media (FaceBook and Instagram)	84	30.5
Sorority	2	0.7
Word of Mouth	7	2.5
Other	4	1.5
missing	0	0.0

The online survey was accessed using the URL link (via email, placed in Zoom chat, or posted on social media) by 96% of the participants, and 4% accessed it using the QR code on the flyer. The average completion time for the survey was 18 minutes, with a minimum of 3 minutes to a maximum of 1 hour and 42 minutes.

Most participants were male (60.2%; see Table 3). The mean age was 40.5 years (*SD* = 10.1), ranging from 18 to 64 years old. The majority of the participants were married (62.9%). Approximately 50% of the participants were high school graduates, had a GED or an Associate's Degree. More than 55% of participants had an income between $25,000 and $74,999. Ninety percent had health insurance, and 88% reported having an office visit with a primary care provider related to diabetes within the last six months.

Table 3. Socio-Demographics of Study Participants (*N* = 275)

Characteristics	***n***	**%**	***M* ± *SD***
Gender			
Male	165	60.0	
Female	109	39.6	
Missing	1	0.4	
Age			40.5 ± 10.1
Missing	0	0.0	
Marital Status			
Single	38	13.8	
Married	173	62.9	
Separated	24	8.7	
Divorced	29	10.5	
Widowed	5	1.8	
Partnered	6	2.2	
Missing	0	0.0	
Education level			
Less than 11th grade	16	5.8	
High school graduate/GED or equivalent	108	39.3	
Associate's Degree	73	26.5	
Bachelor's Degree	54	19.6	
Master's Degree	20	7.3	
Doctorate or Ph.D.	4	1.5	
Missing	0	0.0	

Characteristics	***n***	**%**	***M* ± *SD***
Income			
Less than $25,000	57	20.7	
$25,000 to $49,999	82	29.8	
$50,000 to $74,999	76	27.6	
$75,000 to $99,999	42	15.3	
$100,000 or greater	14	5.1	
I prefer not to answer	4	1.5	
Missing	0	0.0	
Health Insurance			
Yes	246	89.5	
No	26	9.5	
Missing	3	1.0	

Note. *M* = Mean; *SD* = Standard Deviation; GED = graduate education development

Clinical Characteristics

The majority of participants were diagnosed with T2DM by a physician provider (see Table 4). The participant's mean age at diagnosis was 34 years (*SD*= 9.44) and the mean number of years living with diabetes was 6.6 (*SD* = 5.09). About 55% of participants reported their HbA1c was not at the recommended level, with a mean HbA1c of 9% (*SD* = 2.9). Additionally, more than 50% of participants reported that blood pressure and body mass index were at the recommended level. However, obesity was reported as a diabetes-related comorbidity in 19% of the participants.

Ninety-five percent of the participants reported taking oral medications, insulin injections, or both. Many participants were diagnosed with diabetes-related comorbidities by their healthcare providers. The most frequently reported diabetes-related comorbidities were chronic kidney disease, hypertension, hyperlipidemia, and obesity. Although lower extremity amputation related to diabetes was part of the exclusion criteria, 45% of participants reported having diabetes foot-related problems.

Table 4. Clinical Characteristics of Study Participants (*N* = 275)

Characteristics	*n*	%	*M* ± *SD*
HCP who diagnosed T2DM			
Nurse Practitioner	43	15.6	
Physician	167	60.7	
Physician Assistant	65	23.6	
Missing	0	0.0	
Age HCP diagnosed T2DM			34.0 ± 9.4
Missing	0	0.0	
Number of years diagnosed T2DM			6.6 ± 5.1
Missing	0	0.0	
Last self-reported HbA1c			9.0 ± 2.9
Missing	7	1.4	
Number of reported diabetes-related comorbidities			2.0 ± 1.5
Missing	12	4.3	
Reported diabetes-related comorbidities			
Chronic Kidney Disease (related to T2DM)	98	18.9	
Heart Disease	31	6.0	
Heart Failure	11	2.1	
Hyperlipidemia	92	17.8	
Hypertension	99	19.1	
Neuropathy (related to T2DM)	47	9.1	
Obesity	99	19.1	
Peripheral Arterial Disease	13	2.5	
Retinopathy (related to T2DM)	27	5.2	
Other	1	0.2	
Diabetes-related foot problems, ulcers, or infection			
Yes	126	45.8	
No	148	53.8	
Missing	1	0.4	

Note. *M* = Mean; *SD* = Standard Deviation; HbA1c = Hemoglobin A1c; HCP = Healthcare Provider;

T2DM = Type 2 Diabetes Mellitus

Seventy-three percent participated in a formal diabetes education class with a diabetes educator or registered dietitian at least once since diagnosis. About 71% of participants reported a family history of T2DM, with some participants having a history of gestational diabetes. Feeling supported by others related to living with T2DM was reported by 94.5% of the participants (see Table 5).

Table 5. Clinical Characteristics of Study Participants Continued (*N* = 275)

Characteristics	***n***	**%**
Participated in a formal diabetes education class with a diabetes educator or registered dietitian		
Yes	201	73.1
No	74	26.9
missing	0	0.0
Risk factors for T2DM		
Family history of T2DM	211	71.3
Gestational diabetes	32	10.8
None	53	17.9
Type of medications prescribed for T2DM		
Oral medications	198	51.7
Insulin injections	160	41.8
Non-insulin injections	25	6.5
Feel supported living with T2DM by:		
Family	193	29.1
Friends	132	19.9
Healthcare provider	148	22.3
Partner	50	7.5
Spouse	139	20.9
Other	2	0.3

Note. *M* = Mean; *SD* = Standard Deviation; HbA1c = Hemoglobin A1c; HCP = Healthcare Provider; T2DM = Type 2 Diabetes Mellitus

Research Questions 1a-c

What is the level of self-care maintenance, self-care monitoring, and self-care management in non-Hispanic Black adults living with T2DM as measured by the Self-Care of Diabetes Inventory (SCODI)?

Self-Care of Diabetes in the Study Participants

Self-care maintenance (median = 62.5), self-care monitoring (median = 47.1) and self-care management without insulin (median = 62.5), and self-care management with insulin (median = 61.1) were inadequate in the study participants with median scores less than 70 (See Table 6). The lowest median score was for self-care monitoring. The self-care monitoring items asked about behaviors related to monitoring blood glucose, blood pressure, weight, foot care, and signs and symptoms of hypoglycemia and hyperglycemia. Self-care maintenance items asked about participation and length of physical activity, smoking, alcohol intake, measures to prevent illness, eating habits, medication use, provider appointments, and obtaining screening tests on time. Self-care management items asked about checking blood glucose and insulin use. Additionally, self-care management items asked what actions were taken for symptoms of hyperglycemia or hypoglycemia, reflection on what could have contributed to symptoms, and whether advice was sought from a support person or healthcare provider.

The examination of self-care confidence was not included in this study. The scores for self-care confidence were not adequate, with a median score of less than 70 indicating low levels of self-care confidence in the participants. This finding demonstrates the need for further investigation into its influence on the self-care of diabetes and diabetes distress in this sample.

Table 6. Self-Care of Diabetes Inventory Scale Scores

Scale	*n*[*]	*M*	*SD*	Median	Q1-Q3	Minimum	Maximum
Self-care maintenance	266 (9)	64.1	16.0	62.5	52.1–75.0	25.0	100.0
Self-care monitoring	267 (8)	46.6	11.8	47.1	38.2–52.9	0.0	70.6
Self-care management without insulin use	266 (9)	63.4	15.6	62.5	53.1–75.0	0.0	100.0
Self-care management with insulin use	264 (11)	61.2	16.7	61.1	52.8–72.2	0.0	100.0
Self-care confidence	264 (11)	64.6	16.6	63.6	54.6–74.4	4.6	100.0

Note. [*] Numbers are *n* (missing). *M* = Mean; *SD* = Standard Deviation; *Q1-Q3* = 25th – 75th percentile; Scale score of <70 = inadequate self-care

Research Question 2

What is the level of overall diabetes distress and its subscales of emotional burden, regimen distress, interpersonal distress, and physician distress in non-Hispanic Black adults living with T2DM as measured by the Diabetes Distress Scale 17 (DDS17)?

Diabetes Distress in Study Participants

Diabetes distress was the primary independent variable of interest in this study for examining its relationship to the concepts of self-care of diabetes identified in the *Theory of Self-Care of Chronic Illness* in the study sample. On average, the study participants experienced a high level of diabetes distress overall (*M*=3.0). Regarding the diabetes distress subscales, the participants, on average experienced moderate to high levels of distress across all the subscales. The emotional burden was the highest (*M*=3.1), followed by regimen distress (*M*=3.1). The lowest diabetes distress subscale was physician distress (*M*=2.9) which was still a moderate level of distress on average.

Table 7. Diabetes Distress Scale Scores for Study Participants

Scale	*n*[*]	Mean	Standard Deviation
Total Diabetes Distress Score	252 (23)	3.0	1.1
Emotional Burden Subscale	265 (10)	3.1	1.1
Physician Distress Subscale	268 (7)	2.9	1.3
Regimen Distress Subscale	270 (5)	3.1	1.3
Interpersonal Distress Subscale	273 (2)	2.9	1.2

Note. [*] Numbers are *n* (missing). Diabetes Distress scoring = < 2.0 little or no distress; 2.0-2.9 moderate distress; ≥ 3.0 high distress

Research Question 3a

Is diabetes distress associated with adequate self-care maintenance as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

Self-care Maintenance and Diabetes Distress

Nine independent variables were entered into a median regression model for each dependent variable to answer research question 3a. The Pseudo R^2 for this median regression of self-care maintenance scores was 0.241. Income (*b* = 0.233, *p* < .001), last self-reported HbA1c (*b* = -1.933, *p* < .001), and the number of reported diabetes-related comorbidities (*b* = 3.104,

$p < .001$) were significantly associated with self-care maintenance. In median regression modeling of self-care maintenance, age, gender, education level, health insurance, duration of diagnosed T2DM, and total diabetes distress score were not statistically significant (see Table 8).

Table 8. Median Regression Modeling of Self-Care Maintenance (*N* = 231)

Variables	***Coefficient***	**95% CI**	***p-value***
Age in years	0.195	[-0.046, 0.436]	0.112
Gender (male vs. female)	-0.745	[-5.086, 3.596]	0.735
Education level (high school or less vs. Associate’s Degree or higher)	-1.070	[-6.028, 3.888]	0.671
Income ($25,000 increments)	0.233	[0.148, 0.318]	$<0.001^{***}$
Health insurance (insured vs. not insured)	1.937	[-5.409, 9.282]	0.604
Duration of diagnosed T2DM in years	-0.280	[-0.758, 0.198]	0.250
Last self-reported HbA1c (%)	-1.933	[-2.752, -1.114]	$<0.001^{***}$
Number of reported diabetes-related comorbidities	3.104	[1.705, 4.503]	$<0.001^{***}$
Total diabetes distress score	0.970	[-1.015, 2.955]	0.337
Pseudo R^2	**0.241**		

Note. HbA1c = Hemoglobin A1c, T2DM = Type 2 Diabetes. $^{***}p<0.001$

The unit increase for income was $25,000. As income increased by $25,000, the predicted median self-care maintenance score increased by 0.233, adjusting for the other independent variables in the model. The unit increase for HbA1c was one percent. As HbA1c increased by 1%, the predicted median self-care maintenance score decreased by 1.933, adjusting for the other independent variables in the model. The unit increase for reported diabetes-related comorbidities was one comorbidity. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care maintenance score increased by 3.104, adjusting for the other independent variables in the model.

Research Question 3b

Is diabetes distress associated with adequate self-care monitoring as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

Self-Care Monitoring and Diabetes Distress

Nine independent variables were entered into a median regression model for each dependent variable to answer research question 3b. The Pseudo R^2 for this median regression of self-care monitoring scores was 0.185. Income ($b = 0.154$, $p < .001$), last self-reported HbA1c ($b = -1.218$, $p < .001$), the number of reported diabetes-related comorbidities ($b = 2.085$, $p < .001$), and total diabetes distress score ($b= 1.872$, $p =.008$) were significantly associated with self-care monitoring. In median regression modeling of self-care monitoring, age, gender, education level, health insurance, and duration of diagnosed T2DM were not statistically significant (see Table 9).

Table 9. Median Regression Modeling of Self-Care Monitoring (*N* = 231)

Variables	*Coefficient*	95% CI	*p-value*
Age in years	0.097	[-0.070, 0.265]	0.252
Gender (male vs. female)	-1.226	[-4.253, 1.800]	0.425
Education level (high school or less vs. Associate’s Degree or higher)	0.591	[-2.888, 4.069]	0.738
Income ($25,000 increments)	0.154	[0.093, 0.215]	$<0.001^{***}$
Health insurance (insured vs. not insured)	1.149	[-3.912, 6.210]	0.655

Variables	***Coefficient***	**95% CI**	***p-value***
Duration of diagnosed T2DM in years	-0.108	[-0.434, 0.218]	0.513
Last self-reported HbA1c (%)	-1.218	[-1.779, -0.657]	$<0.001^{***}$
Number of reported diabetes-related comorbidities	2.085	[1.121, 3.048]	$<0.001^{***}$
Total diabetes distress score	1.872	[0.505, 3.238]	0.008^{**}
Pseudo R^2	**0.185**		

Note. HbA1c = Hemoglobin A1c, T2DM = Type 2 Diabetes. $^{**}p<0.01$. $^{***}p<0.001$

As income increased by $25,000, the predicted median self-care monitoring score increased by 0.154. As HbA1c increased by 1%, the predicted median self-care monitoring score decreased by 1.218. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care monitoring score increased by 2.085. The unit increase for the total score for diabetes distress was one point. As the total score for diabetes distress increased by one point, the predicted median self-care monitoring score increased by 1.872, adjusting for the other independent variables in the model.

Research Question 3c

Is diabetes distress associated with adequate self-care management as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

Self-Care Management Without Insulin Use and Diabetes Distress

Nine independent variables were entered into a median regression model for each dependent variable to answer research question 3c. The Pseudo R^2 for this median regression of self-care management without insulin use scores was 0.153. Income (*b* = 0.141, *p* < .001), last self-reported HbA1c (*b* = -1.783, *p* < .001), number of reported diabetes-related comorbidities (*b* = 2.721, *p* < .001), and total diabetes distress score (*b*= 3.740, *p* <.001) were significantly associated with self-care management without insulin use. In median regression modeling of self-care management without insulin use, age, gender, education level, health insurance, and duration of diagnosed T2DM were not statistically significant (see Table 10).

Table 10. Median Regression Modeling of Self-Care Management Without Insulin Use (*N* = 231)

Variables	*Coefficient*	95% CI	*p-value*
Age in years	0.059	[-0.147, 0.265]	0.574
Gender (male vs. female)	-1.283	[-4.992, 2.426]	0.496
Education level (high school or less vs. Associate's Degree or higher)	-2.619	[-6.867, 1.629]	0.226
Income ($25,000 increments)	0.141	[0.069, 0.213]	<0.001***
Health insurance (insured vs. not insured)	-0.700	[-7.131, 5.731]	0.830
Duration of diagnosed T2DM in years	-0.353	[-0.765, 0.058]	0.092
Last self-reported HbA1c (%)	-1.783	[-2.478, -1.088]	<0.001***
Number of reported diabetes-related comorbidities	2.721	[1.525, 3.916]	<0.001***
Total diabetes distress score	3.740	[2.042, 5.437]	<0.001***
Pseudo R^2	**0.153**		

Note. HbA1c = Hemoglobin A1c, T2DM = Type 2 Diabetes. $^{***}p<0.001$

As income increased by $25,000, the predicted median self-care management without insulin use score increased by 0.141. As HbA1c increased by 1%, the predicted median self-care management without insulin use score decreased by 1.783. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care management without insulin use score increased by 2.721. As the total score for diabetes distress increased by one point, the predicted median self-care management without insulin use score increased by 3.740.

Self-Care Management with Insulin Use and Diabetes Distress

Nine independent variables were entered into a median regression model for each dependent variable to answer research question 3c. The Pseudo R^2 for this median regression of self-care management with insulin scores was 0.137. Income ($b = 0.099$, $p < .001$), last self-reported HbA1c ($b = -1.921$, $p < .001$), number of reported diabetes-related comorbidities ($b = 4.070$, $p < .001$), and total diabetes distress score ($b= 4.117$, $p < .001$) were significantly associated with self-care management with insulin use. In median regression modeling of self-care management with insulin use, age, gender, education level, health insurance, and duration of diagnosed T2DM were not statistically significant (see Table 11).

Table 11. Median Regression Modeling of Self-Care Management With Insulin Use ($N = 231$)

Variables	*Coefficient*	95% CI	*p-value*
Age in years	-0.171	[-0.417, 0.075]	0.173
Gender (male vs. female)	-1.874	[-6.301, 2.553]	0.405
Education level (high school or less vs. Associate’s Degree or higher)	-2.373	[-7.450, 2.704]	0.358
Income ($25,000 increments)	0.099	[0.012, 0.187]	0.026*
Health insurance (insured vs. not insured)	-3.702	[-11.390, 3.986]	0.344

Variables	*Coefficient*	95% CI	*p-value*
Duration of diagnosed T2DM in years	-0.020	[-0.529, 0.489]	0.938
Last self-reported HbA1c (%)	-1.921	[-2.753, -1.090]	$<0.001^{***}$
Number of reported diabetes-related comorbidities	4.070	[2.639, 5.502]	$<0.001^{***}$
Total diabetes distress score	4.117	[2.086, 6.148]	$<0.001^{***}$
Pseudo R²	**0.137**		

Note. HbA1c = Hemoglobin A1c; T2DM = Type 2 Diabetes. $^{***}p<0.001$

As income increased by $25,000, the predicted median self-care management with insulin use score increased by 0.099. As HbA1c increased by 1%, the predicted median self-care management with insulin use score decreased by 1.921. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care management with insulin use score increased by 4.070. As the total score for diabetes distress increased by one point, the predicted median self-care management with insulin use score increased by 4.117.

Research Question 4a

Is emotional burden, physician distress, regimen distress, and interpersonal distress, associated with adequate self-care maintenance as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

Self-Care Maintenance and Diabetes Distress Subscales

Twelve independent variables were entered into a median regression model for each dependent variable to answer research question 4a. The Pseudo R^2 for this median regression of self-care maintenance scores was 0.243. Income ($b = 0.265$, $p < .001$), last self-reported HbA1c ($b = -1.780$, $p < .001$), and the number of reported diabetes-related comorbidities ($b = 3.010$, $p < .001$) were significantly associated with self-care maintenance. In median regression modeling of self-care maintenance, age, gender, education level, health insurance, duration of diagnosed T2DM, and the diabetes distress subscale scores (emotional burden, physician distress, regimen distress, and interpersonal distress) were not statistically significant (see Table 12).

Table 12. Median Regression Modeling of Self-Care Maintenance (*N* = 231)

Variables	***Coefficient***	**95% CI**	***p-value***
Age in years	0.181	[-0.048, 0.409]	0.120
Gender (male vs. female)	-0.461	[-4.542, 3.621]	0.824
Education level (high school or less vs. Associate’s Degree or higher)	-1.774	[-6.485, 2.937]	0.459
Income ($25,000 increments)	0.265	[0.183, 0.346]	$<0.001^{***}$
Health insurance (insured vs. not insured)	2.912	[-4.006, 9.830]	0.408
Duration of diagnosed T2DM in years	-0.171	[-0.620, 0.279]	0.455
Last self-reported HbA1c (%)	-1.780	[-2.557, -1.003]	$<0.001^{***}$
Number of reported diabetes-related comorbidities	3.010	[1.682, 4.337]	$<0.001^{***}$
Emotional burden subscale score	1.026	[-2.071, 4.123]	0.514
Physician distress subscale score	0.638	[-2.437, 3.713]	0.683
Regimen distress subscale score	-0.595	[-4.385, 3.194]	0.757
Interpersonal distress subscale score	-0.252	[-3.444, 2.940]	0.876
Pseudo R^2	**0.243**		

Note. HbA1c = Hemoglobin A1c, T2DM = Type 2 Diabetes. $^{***}p<0.001$

As income increased by $25,000, the predicted median self-care maintenance score increased by 0.265, adjusting for the other independent variables in the model. As HbA1c increased by 1%, the predicted median self-care maintenance score decreased by 1.780, adjusting for the other independent variables in the model. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care maintenance score increased by 3.010, adjusting for the other independent variables in the model.

Research Question 4b

Is emotional burden, physician distress, regimen distress, and interpersonal distress, associated with adequate self-care monitoring as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

Self-Care Monitoring and Diabetes Distress Subscales

Twelve independent variables were entered into a median regression model for each dependent variable to answer research question 4b. The Pseudo R^2 for this median regression of self-care monitoring scores was 0.187. Income ($b = 0.160$, $p < .001$), last self-reported HbA1c ($b = -1.229$, $p < .001$), and the number of reported diabetes-related comorbidities ($b = 2.080$, $p < .001$) were significantly associated with self-care monitoring. In median regression modeling of self-care monitoring, age, gender, education level, health insurance, duration of diagnosed T2DM, and the diabetes distress subscale scores were not statistically significant (see Table 13).

Table 13. Median Regression Modeling of Self-Care Monitoring (*N* = 231)

Variables	*Coefficient*	95% CI	*p-value*
Age in years	0.089	[-0.080, 0.257]	0.300
Gender (male vs. female)	-0.872	[-3.894, 2.150]	0.570
Education Level (high school or less vs. Associate's Degree or higher)	0.419	[-3.070, 3.908]	0.813
Income ($25,000 increments)	0.160	[0.098, 0.222]	<0.001***
Health insurance (insured vs. not insured)	0.720	[-4.336, 5.776]	0.779
Duration of diagnosed T2DM in years	-0.134	[-0.459, 0.191]	0.416
Last self-reported HbA1c (%)	-1.229	[-1.794, -0.664]	<0.001***
Number of reported diabetes-related comorbidities	2.080	[1.111, 3.049]	<0.001***
Emotional burden subscale score	1.065	[-1.309, 3.439]	0.378
Physician distress subscale score	0.466	[-1.819, 2.751]	0.688
Regimen distress subscale score	0.743	[-2.127, 3.614]	0.610
Interpersonal distress subscale score	-0.382	[-2.737, 1.973]	0.749
Pseudo R^2	**0.187**		

Note. HbA1c = Hemoglobin A1c, T2DM = Type 2 Diabetes. $^{***}p<0.001$

As income increased by $25,000, the predicted median self-care monitoring score increased by 0.160. As HbA1c increased by 1%, the predicted median self-care monitoring score decreased by 1.229. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care monitoring score increased by 2.080.

Research Question 4c

Is emotional burden, physician distress, regimen distress, and interpersonal distress, associated with self-care management as measured by the Self-Care of Diabetes Inventory while controlling for demographics (age, gender), social determinants of health (income, education level, health insurance), and clinical characteristics (self-reported HbA1c, duration of diagnosed

T2DM in years, and the number of reported diabetes-related comorbidities) in non-Hispanic Black Adults with T2DM?

Self-Care Management Without Insulin Use and Diabetes Distress Subscales

Twelve independent variables were entered into a median regression model for each dependent variable to answer research question 4c. The Pseudo R^2 for this median regression for self-care management without insulin use scores was 0.155. Education level (*b* = -4.619, *p* =0.039), Income (*b* = 0.164, *p* < .001), last self-reported HbA1c (*b* = -1.749, *p*< .001), and the number of reported diabetes-related comorbidities (*b* = 2.796, *p* < .001) were significantly associated with self-care management without insulin use. In median regression modeling of self-care management without insulin use, age, gender, health insurance, duration of diagnosed T2DM, and the diabetes distress subscale scores were not statistically significant (see Table 14).

Table 14. Median Regression Modeling of Self-Care Management Without Insulin Use (*N* = 231)

Variables	*Coefficient*	95% CI	*p-value*
Age in years	0.057	[-0.155, 0.270]	0.594
Gender (male vs. female)	-1.188	[-4.989, 2.613]	0.538
Education Level (high school or less vs. Associate's Degree or higher)	-4.619	[-9.014, -0.224]	0.039^{*}
Income ($25,000 increments)	0.164	[0.088, 0.240]	$<0.001^{***}$
Health insurance (insured vs. not insured)	-0.839	[-7.439, 5.760]	0.802
Duration of diagnosed T2DM in years	-0.388	[-0.810, 0.034]	0.071
Last self-reported HbA1c (%)	-1.749	[-2.469, -1.028]	$<0.001^{***}$
Number of reported diabetes-related comorbidities	2.796	[1.559, 4.033]	$<0.001^{***}$

Variables	***Coefficient***	**95% CI**	***p-value***
Emotional burden subscale score	1.761	[-1.119, 4.641]	0.229
Physician distress subscale score	1.270	[-1.595, 4.135]	0.383
Regimen distress subscale score	-0.177	[-3.728, 3.373]	0.922
Interpersonal distress subscale score	0.885	[-2.095, 3.864]	0.559
Pseudo R^2	**0.155**		

Note. HbA1c = Hemoglobin A1c; T2DM = Type 2 Diabetes. $^{*}p<0.05$, $^{***}p<0.001$

The predicted median self-care management without insulin use score was 4.619 points lower for those with high school or less education compared to an Associate's Degree or higher education level, adjusting for the other independent variables in the model. As income increased by $25,000, the predicted median self-care management without insulin use score increased by 0.164. As HbA1c increased by 1%, the predicted median self-care management without insulin use score decreased by 1.749. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care management without insulin use score increased by 2.796.

Self-Care Management With Insulin Use and Diabetes Distress Subscales

Twelve independent variables were entered into a median regression model for each dependent variable to answer research question 4c. The Pseudo R^2 for this median regression of self-care management with insulin use scores was 0.141. Income ($b = 0.109$, $p < .001$), last self-reported HbA1c ($b = -1.791$, $p < .001$), and the number of reported diabetes-related comorbidities ($b = 4.144$, $p < .001$) were significantly associated with self-care management with insulin use. In median regression modeling of self-care management with insulin use, age, gender, education level, health insurance, duration of diagnosed T2DM, and the diabetes distress subscale scores were not statistically significant (see Table 15).

Table 15. Median Regression Modeling of Self-Care Management With Insulin Use (*N* = 231)

Variables	*Coefficient*	95% CI	*p-value*
Age in years	-0.089	[-0.339, 0.162]	0.486
Gender (male vs. female)	-2.097	[-6.578, 2.384]	0.357
Education Level (high school or less vs. Associate's Degree or higher)	-1.598	[-6.783, 3.588]	0.544
Income ($25,000 increments)	0.109	[0.018, 0.200]	0.019*
Health insurance (insured vs. not insured)	-2.857	[-10.647, 4.933]	0.471
Duration of diagnosed T2DM in years	-0.152	[-0.667, 0.364]	0.562
Last self-reported HbA1c (%)	-1.791	[-2.643, -0.939]	<0.001***
Number of reported diabetes-related comorbidities	4.144	[2.680, 5.607]	<0.001***
Emotional burden subscale score	-0.286	[-3.681, 3.109]	0.868
Physician distress subscale score	1.953	[-1.428, 5.334]	0.256
Regimen distress subscale score	0.786	[-3.400, 4.972]	0.712
Interpersonal distress subscale score	1.328	[-2.190, 4.847]	0.458
Pseudo R^2	**0.141**		

Note. HbA1c = Hemoglobin A1c; T2DM = Type 2 Diabetes. $^{*}p<0.05$, $^{***}p<0.001$

As income increased by $25,000, the predicted median self-care management with insulin use score increased by 0.109. As HbA1c increased by 1%, the predicted median self-care management with insulin use score decreased by 1.791. As the number of reported diabetes-related comorbidities increased by one, the predicted median self-care management with insulin use score increased by 4.144.

Summary of Significant Findings

Two hundred seventy-five non-Hispanic Black adults with type 2 diabetes (T2DM) living in North Carolina took an online survey to examine relationships between and among the concepts of self-care diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress. The average age of participants was 40 years old, and the average age a healthcare provider diagnosed them with T2DM was 34 years old. Only 37.5% of the participants reported that HbA1c was at the recommended level. The level of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) was inadequate, and the level of diabetes distress was moderate to high in this sample.

Median regression was used to answer the research questions examining associations between diabetes distress and self-care diabetes (self-care maintenance, self-care monitoring, and self-care management) while controlling for other independent variables. Income, last reported HbA1c, and the number of reported diabetes-related comorbidities were statistically significant in predicting median scores of self-care maintenance, self-care monitoring, and self-care management (with and without insulin use) scores, adjusting for other independent variables. The total diabetes distress score was only statistically significant in predicting the median scores of self-care monitoring and self-care management (with and without insulin use), adjusting for other independent variables. The diabetes distress subscale scores (emotional burden, physician distress, regimen distress, and interpersonal distress) were not statistically significant in any of the median regression models.

CHAPTER V: DISCUSSION

This study aimed to describe the concepts of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress in non-Hispanic Black adults ages 18-64 years old living with T2DM in North Carolina. The study also aimed to ascertain if there are relationships between and among the concepts of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes stress in the same population. This chapter presents the interpretation and discussion of the findings of the study. Study limitations, implications for nursing, and future research recommendations are also presented.

Discussion of Findings

Demographic Characteristics

Some of the sociodemographic and clinical characteristics of non-Hispanic Black Adults in this sample were similar to that of non-Hispanic Black adults in previous diabetes studies for education level, having health insurance, duration of years with diabetes, and HbA1c status (Chlebowy et al., 2019; Helgeson et al., 2021; Miller et al., 2016; Presley et al., 2021). A majority of participants in this study were married. Prior studies had varied inclusion of marital status, with less than 30% of participants reporting being married (Bonner et al., 2019; Gumbs, 2020; Hernandez et al., 2014; Miller et al., 2016). Spouse or partner participation can influence the self-care of diabetes, improving glycemic control and lessening diabetes distress of individuals living with diabetes (Gonzalez-Zacarias et al., 2016).

The participants in this study had more noticeable differences in age, gender, and diabetes-related complications. The average age of participants in this sample was younger compared to other studies (Miller et al., 2016; Sherman et al., 2017). Individuals diagnosed at a younger age experience higher levels of distress (Hu et al., 2020; Kasteleyn et al., 2015; Wardian & Sun, 2014). One study reported a possible association between diabetes distress and the duration of diabetes in younger people, which could be more pronounced (Kasteleyn et al., 2015). A National Health and Nutrition Examination Survey (NHANES) found Blacks reported lower ages (*M*= 47.2) at diabetes diagnosis and that diagnosis of diabetes before 40 was greater among Blacks compared to non-Hispanic Whites (Wang et al., 2021). The earlier age at diagnosis participants in this study may increase their risk of diabetes-related complications.

The number of male participants (*n*=165) exceeded that of female participants (*n*=109), likely due to partnering with a fraternity for recruitment. Similar studies in non-Hispanic Blacks have more female participants, or non-Hispanic Black females are the selected population (Gumbs, 2020; Hernandez et al., 2014; Miller, 2011; Miller et al., 2016; Rahim-Williams, 2011).

Social Determinants of Health

An individual's income can contribute to obtaining health insurance. Higher incomes were reported in this sample, whereas incomes were lower in other studies with non-Hispanic Black adults (Chlebowy et al., 2019; Gumbs, 2020; Hernandez et al., 2014; Presley et al., 2021). Income was statistically significant and positively associated with self-care maintenance, self-care monitoring, or self-care management. As income increased, the predicted median self-care maintenance, self-care monitoring, or self-care management scores increased, suggesting a higher level of adequate self-care for diabetes. Health insurance helps with the cost of self-care of diabetes, including access to DSMES, which improves glycemic control and lessens diabetes distress (Gonzalez-Zacarias et al., 2016; Peña-Purcell et al., 2019).

More than half of this study's participants were high school graduates, had a GED or Associate's Degree. Education level was statistically significant and associated with self-care management without insulin use in the model with diabetes subscales. An education level in those with less than high school contributed to lower levels of adequate self-care management without insulin use. A study using Summary of Diabetes Self-Care Activities found an association between lower and higher education levels and diabetes self-care behaviors reported by African-American participants (Hernandez et al., 2014).

Studies indicate having health insurance influences self-care of diabetes behaviors. The majority of the participants in this study reported having health insurance. Health insurance was not significantly associated with self-care maintenance, self-care monitoring, or self-care management. Gumbs (2020) found that participants without health insurance were less likely to engage in health-promoting behaviors in which they had to see a healthcare provider. A majority of the participants in this study reported seeing their healthcare provider within the last six months. A study assessing the relationship between foot care knowledge and practices in African-American adults found that having health insurance can increase foot care knowledge, which is protective in preventing lower extremity complications (Bonner et al., 2019). Interestingly, about half of the participants in this study reported having diabetic foot problems, ulcers, or infections.

Clinical Characteristics

The average duration of diagnosed T2DM was 6.6 years in this sample. In studies with non-Hispanic Black adults that assessed the duration of years with T2DM, it ranged from 1.5 to 41 years (Bonner et al., 2019; Helgeson et al., 2021; Hood et al., 2018; Presley et al., 2020; Rahim-Williams, 2011). The duration of years diagnosed with T2DM was not significantly associated with self-care maintenance, self-care monitoring, or self-care management with or without insulin use. But the longer one has T2DM, the risk of diabetes-related complications and comorbidities increases which can also elevate diabetes distress (Kasteleyn et al., 2015).

The last reported Hba1c (*M* = 9%) of the participants in this study was above the recommended level of <7%. The last self-reported HbA1c was negatively associated with self-care maintenance, self-care monitoring, or self-care management with or without insulin use. As HbA1c increased, the scores of self-care maintenance, self-care monitoring, or self-care management decreased, suggesting a lower level of adequate self-care of diabetes. Similar studies with non-Hispanic Black adults had HbA1c ranging from 7.1-10.1%, comparable to participants in this study (Chlebowy et al., 2019; Hernandez et al., 2014; Miller, 2011; Miller et al., 2016; Presley et al., 2020). Higher HbA1c levels increase the risk of diabetes-related complications.

A majority of participants reported having diabetes-related comorbidities in this sample which was assessed by limited studies with non-Hispanic Black adults (Gumbs, 2020; Hernandez et al., 2014; Hood et al., 2018; Miller et al., 2016; Rahim-Williams, 2011). Studies that assessed diabetes-related comorbidities, hypertension, heart disease, obesity, peripheral artery disease, and peripheral neuropathy were reported (Bonner et al., 2019; Wang et al., 2021). Similar diabetes-related comorbidities, including chronic renal disease, hypertension, hyperlipidemia, and obesity, were reported by participants in this study.

The lower age at diagnosis and the number of reported diabetes-related comorbidities present are concerning for poorer health outcomes. The average number of reported diabetes-related comorbidities was 2.0 in this study. The number of reported diabetes-related comorbidities had statistical significance in self-care maintenance, self-care monitoring, or self-care management with or without insulin use. Although inconclusive, a study reported whether diabetes-related comorbidities could increase the performance of self-care of diabetes activities (Aga et al., 2019). Similarly, in this study, the self-care maintenance score, self-care monitoring, and self-care management score increased as the number of diabetes-related comorbidities increased. This finding differed from previous studies where increased distress was associated with less self-care of diabetes activities (AlOtaibi et al., 2021; Hernandez et al., 2014; Miller, 2011; Summers-Gibson, 2021).

Self-Care of Diabetes and Diabetes Distress

Participants in this study were found to have inadequate levels of self-care maintenance, self-care monitoring, and self-care management. Most studies using SCODI have been conducted outside the United States with reported adequate self-care maintenance and inadequate self-care monitoring and self-care management scores. One study using SCODI included a sample of 207 participants, of which 28% were Black/African-American. No specific analysis of the racial groups was included, and the self-care profile was described as typical. Self-care maintenance was adequate (median=75), and self-care management was inadequate (median=55.6) in the study with participants from Italy and the United States (Luciani et al., 2021).

The SCODI tool has not been used in studies specifically with non-Hispanic Black adults with T2DM. Therefore, limiting the ability to compare the findings of this study with a similar sample. In this study, participants self-care maintenance score was higher but less than adequate, and self-care monitoring was the lowest. Self-care monitoring daily activities include monitoring blood glucose, weight, blood pressure, foot care, and monitoring for symptoms of hypoglycemia and hyperglycemia. A study found challenges to blood glucose monitoring were common and that participants avoided checking blood glucose and did not see the significance of performing the task (Polonsky et al., 2014).

The Summary of Diabetes Self-Care Activities (SDSCA) was the tool most frequently used in studies with non-Hispanic Black adults (Helgeson et al., 2020; Hernandez et al., 2014; Hood et al., 2018; Miller et al., 2016). This tool measures the frequency of performance of self-care behaviors over seven days, similar to self-care maintenance in SCODI, but with no specific assessment of self-care monitoring or self-care management. SDSCA is not comparable to SCODI.

Participants in this sample had high levels of diabetes distress on average ($M = 3.0$). Considering the diabetes distress subscales, participants experienced high levels of diabetes distress with emotional burden and regimen distress. African Americans experience higher levels of diabetes distress than non-Hispanic Whites (Peyrot et al., 2018; Presley et al., 2020). Most of the participants in this study reported having health insurance, an office visit to health care providers within the last six months, and an income of or higher than $25,000 per year. Studies with non-Hispanic Black adults indicated moderate to high levels of diabetes distress in persons with and without health insurance and at various income levels (Chlebowy et al., 2019; Hood et al., 2018; Miller, 2011; Presley et al., 2021).

The total diabetes distress score was statistically significantly associated with self-monitoring and self-care management with and without insulin use. There was no statistically significant association between total diabetes distress score and self-care maintenance. Other studies have reported moderate regimen distress associated with self-care behaviors that occur with self-care maintenance (Hood et al., 2018; Presley et al., 2021). As the total diabetes distress score increased in this sample, self-care monitoring and self-care management scores with and without insulin use increased, meaning the level of self-care may be higher.

Diabetes distress was also associated with higher levels of self-care monitoring and self-care management in this sample. As previously reported, an increasing number of reported diabetes-related comorbidities was associated with higher levels of all self-care of diabetes measures. Keeping in mind, they were still considered less than adequate in this sample. Initially, one may expect a decrease in self-care of diabetes measures with an increased level of diabetes distress. This finding may suggest the demands of having multiple diabetes-related comorbidities may result in more self-care monitoring and self-care management activities, including more decision-making contributing to diabetes distress. There are limited comparative studies in non-Hispanic Black adults. One study in a population with moderate to severe diabetes distress reported that increased diabetes distress was also associated with increased diabetes self-care activities (Akbari et al., 2022). The scores for self-care of diabetes measures in this sample were less than adequate and signal the importance of screening/assessment of diabetes distress and the use of interventions to decrease the level of diabetes distress and evaluate their effectiveness.

Increased engagement in self-care of diabetes has a vital role in achieving glycemic targets to decrease complications. DSMES (Diabetes Self-Management Education and Support) effectively reduces diabetes distress. A feasibility study examined the effectiveness of interventions in individuals with diabetes and hypertension that included 6% African Americans. This study reported a decrease in the diabetes distress subscales (emotional burden and regimen distress) after the twelve-week intervention and an increase in the performance of self-care of diabetes activities (Misra et al., 2021). Although not a comparative study, it provides further evidence that DSMES effectively reduces diabetes distress.

The total score of diabetes distress subscales (emotional burden, physician distress, regimen distress, and interpersonal distress) did not reveal statistically significant associations in this sample. This result was an unexpected finding as other studies have reported moderate regimen distress associated with self-care behaviors that occur with self-care maintenance (Hood et al., 2018; Presley et al., 2021). The number of items in the subscales is lower: five for emotional burden, four for physician distress, five for regimen distress, and three for interpersonal distress. The subscales contribute to the summative score for diabetes distress. Both of these may have contributed to the unexpected findings, given the statistically significant result of the total score of diabetes distress in self-care monitoring and self-care management with and without insulin use. Healthcare providers often want to share all the information related to diabetes management in one encounter, which can contribute to diabetes distress. Reviewing the subscales to identify specific areas is invaluable in providing patient-centered healthcare. For example, the ability to measure the degree of regimen distress will support developing an individualized plan of care. A clinician can identify if the area of distress is related to self-care maintenance, self-monitoring, or self-care management. The literature supports this approach (Wardian & Sun, 2014).

Conclusion

Diabetes is a complex chronic condition requiring a multifaceted approach. In this sample of non-Hispanic Black adults, the self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress demonstrated a positive association indicating that as diabetes distress increased, so did the level of self-care of diabetes measures. An increase in self-care of diabetes is desired to improve self-management of T2DM, but the associated increase in diabetes distress is challenging. Previous studies showed as diabetes distress increased, diabetes self-care behaviors decreased, contributing to poor glycemic control and poorer health outcomes. The findings indicate the need for more studies to assess further how diabetes distress influences the self-care of diabetes.

The middle-range *Theory of Self-Care of Chronic Illness* provides three concepts addressing self-care that can be applied to most chronic illnesses. The concepts are designed to flow as feedback loops that interact with each other, providing reflection, evaluation, and readjustment of self-care behaviors to achieve or maintain the stability of chronic illness. The process can be individualized to meet the goals of care. Ongoing evaluation of self-care of diabetes and diabetes distress in non-Hispanic Black adults is needed. The Diabetes Distress Scale 17 has been used consistently for over twenty years and provides a comprehensive assessment of diabetes distress. Numerous tools to measure diabetes self-care have been used over time, with the Summary of Diabetes Self-Care Activities utilized most often. This tool measures the frequency of performance of self-care behaviors over seven days, similar to some of the activities in self-care maintenance measured by SCODI, but with no specific assessment of self-care monitoring or self-care management. Reflection and decision-making are included in SCODI, which was developed and guided by the *Theory of Self-Care of Chronic Illness*.

This study added to the body of knowledge, but there is still an opportunity to expand knowledge further. Ongoing comprehensive assessment and evaluation utilizing a consistently reliable and valid instrument to measure the self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) will be key in identifying areas of inadequate self-care of diabetes. Assessing and measuring both diabetes distress and self-care of diabetes will lead to the development of evidence-based targeted, culturally appropriate interventions to ultimately improve health outcomes in non-Hispanic Black adults living with type 2 diabetes.

Implications for Nursing

Nurses, particularly advanced practice nurses (APNs), can develop innovative ways to support non-Hispanic Black adults living with T2DM. The development and implementation of diabetes management programs and centers led by nurses can provide additional resources for this population. Incorporating the use of technology via telehealth, virtual peer support groups, and text messaging will be essential for self-care interventions, along with the development of brief screening tools to assess self-care behaviors. All of these need longitudinal research studies to evaluate the effect of self-care behaviors and self-care interventions on health outcomes.

More advanced practice nurses who are board certified in advanced diabetes management are needed to facilitate ongoing assessment and evaluation of self-care of diabetes and diabetes distress. Individuals with this credential can manage complex patients and support them with therapeutic problem-solving. APNs working within their scope of practice can adjust medications and manage acute and chronic complications and associated comorbidities. They can also counsel on self-care behaviors, assess diabetes distress and participate in research and mentoring (Association of Diabetes Care & Education Specialists, n.d.). The inclusion of a diabetes concentration in nurse practitioner programs can also prepare APNs to care for non-Hispanic Black adults living with T2DM (McGrath et al., 2022). APN involvement on the legislative level is needed to remove practice barriers and improve health policies affecting patient care.

One study found challenges with self-monitoring of glucose and included strategies the nurses, particularly advanced practice nurses, could implement and evaluate. Clinicians' strategies were acknowledging task completion versus emphasizing the results and exploring why blood glucose is not done. Individuals may have run out of test strips, had challenges with time management, stressful life events, or were overwhelmed with daily tasks (diabetes distress). Improving provider-patient communication by explaining the rationale for self-monitoring glucose and the influence of food intake on glycemic control can support the patient's understanding and engagement in task performance. Literature supports improving communication and collaboration between healthcare providers and individuals living with diabetes (Peimani et al., 2020; Polonsky et al., 2014; Skinner et al., 2019). APNs can aid in interprofessional collaboration and communication to support non-Hispanic Black adults in the self-care of diabetes.

A better understanding of the relationship between self-care of diabetes and diabetes distress in non-Hispanic Black adults supports national guidelines such as Healthy People 2030. Objectives for individuals diagnosed with diabetes are improving glucose monitoring of individuals using insulin, reduction of individuals with an HbA1c greater than 9%, and decreasing complications such as chronic kidney disease and lower extremity amputations (Office of Disease Prevention and Health Promotion, n.d.b).

Diabetes distress is the concern individuals living with diabetes experience regarding managing diabetes over time (Diabetes Distress Assessment & Resource Center, n.d.). The significance of diabetes distress in self-management is growing with recommendations to include assessing, intervening, and evaluating diabetes distress as part of routine diabetes care (American Diabetes Association Professional Practice Committee, 2021c; Association of Diabetes Care and Education Specialists, 2021). Diabetes distress can begin with the initial diagnosis. Therefore, open dialogue about this emotional response should occur early (Skinner et al., 2019). Effective communication between the provider and patient is essential. One study found that poor communication with a provider can lead to poorer health outcomes and influence diabetes self-care (Peimani et al., 2020). APNs can play a vital role in assessing diabetes distress by utilizing a validated instrument such as the Diabetes Distress Scale 17. APNs can collaborate with health systems' electronic health teams to integrate instruments that measure self-care of diabetes and diabetes distress into the electronic health record and develop a frequency plan for assessing these concepts that influence glycemic control.

The referral to DSMES is recommended and can be facilitated by APNs with referral to diabetes educators and registered dieticians ((Davis et al., 2022; Powers et al., 2020). Most importantly, APNs can support the education and strategies of DSMES by asking individuals about what they learned, providing clarification as needed, and asking about strategies implemented regularly to reinforce the importance of diabetes education. One study with a focus group of African American women with T2DM shared the difficulty of applying the concepts of diabetes education and its role in diabetes self-management (Onwudiwe et al., 2011). Bridging this gap is an ideal place for APNs to support non-Hispanic Black adults in applying knowledge learned in DSMES.

Lastly, APNs can aid in the language of diabetes. A stigma is associated with the diagnosis and terminology used by healthcare providers. Some examples are not identifying the person by diagnosis, avoiding non-compliant in describing a person’s actions, and shifting from the control of diabetes. An alternative language is a person living with diabetes and focusing on what the person is doing or engaging in self-care of diabetes and whether targets or goals are being met (Dickinson et al., 2017).

This study found the level of self-care of diabetes was less than adequate, and the level of diabetes distress was moderate to high in this sample of non-Hispanic Black adults with T2DM. The practice of self-care is an ongoing process that aligns with nursing. The *Theory of Self-Care* *of Chronic Illness* allows one to examine each concept individually and comprehensively. Using the self-care concepts from the *Theory of Self-Care of Chronic Illness* provides a measurable guide for further research. The development of a scientific statement about self-care of diabetes and diabetes distress can provide consistent shared terminology along with an algorithm for assessment, development of evidence-based targeted, culturally- appropriate interventions, and evaluation.

Future Research

More research is needed on effective strategies to recruit non-Hispanic Black adults to participate in research to generalize findings and develop more individualized or community-focused interventions. There are limited comparative quantitative studies examining the relationship between self-care of diabetes and diabetes distress in non-Hispanic Black Adults. The consistent use of a theory-guided instrument provides the opportunity for a comprehensive assessment of self-care of diabetes and the ability to evaluate targeted, culturally appropriate intervention as well as provide comparative studies. Qualitative studies in non-Hispanic Black adults explored diabetes self-care and diabetes distress individually and together. They offered insight into the lived experiences of the individuals and could have been strengthened by quantifying the concepts. The mixed methods research approach is an opportunity for future studies to examine the relationship between the self-care of diabetes and diabetes distress. The findings of diabetes distress predicting higher levels of self-care of diabetes led to the need for more inquiry.

The practice of self-care is an ongoing process that aligns with nursing. The *Theory of Self-Care of Chronic Illness* allows one to examine each concept individually and comprehensively. Using the self-care concepts from the *Theory of Self-Care of Chronic Illness* provides a measurable guide for further research. The development of a scientific statement about self-care of diabetes and diabetes distress can provide consistent shared terminology along with an algorithm for assessment, development of evidence-based targeted, culturally-appropriate interventions, and evaluation (Jaarsma et al., 2020; Viscardi et al., 2022).

There are many pieces to the puzzle in the self-care of diabetes. A personal discussion with the healthcare provider about the self-care of diabetes and diabetes distress can contribute to non-Hispanic Black adults' engagement in self-care of diabetes activities with lower levels of diabetes distress. More research is needed to evaluate whether diabetes distress interventions reduce elevated levels of diabetes distress. A systematic review of psychological interventions in individuals with diabetes and increased diabetes distress revealed a scarce number of studies, and none included non-Hispanic Black adults (Schmidt et al., 2018). Interventions by the developers of the DDS 17 highlight having meaningful encounters and conversations with individuals with T2DM (Fisher et al., 2019; Rariden, 2019). Time and evaluation/coding challenges can be a barrier, and more studies are needed to evaluate these recommended interventions. Future intervention studies using SCODI and DDS17 to provide baseline assessment and culturally appropriate DSMES are needed in non-Hispanic Black to continue advancing knowledge to improve health outcomes. The findings indicate the importance of screening and assessment of diabetes distress, interventions to decrease the level of diabetes distress, and evaluating their effectiveness. More studies are needed to assess how diabetes distress influences the self-care of diabetes in non-Hispanic Black adults.

There are future opportunities for research with this sample via secondary data analysis. Future research can examine age/gender differences, the number of reported diabetes-related comorbidities/age, and social support/level of diabetes distress. Further investigation of self-care confidence as an influencing factor on self-care measures and the level of diabetes distress in this sample can also be examined.

Limitations of the Study

There are limitations to the generalizability of findings from this study. Convenience sampling was used and may not be representative of non-Hispanic Blacks ages 18-64 who live outside of North Carolina. The study’s cross-sectional nature may not promote a consistent understanding of the longitudinal needs and self-care of diabetes in non-Hispanic Black adults. Self-reported surveys were used for data collection. Surveys rely on participants' self-reports and possible superficial responses or response bias. The researcher aimed to address this by selecting instruments with good psychometric validity and reliability. Other limitations include user competency with mobile devices to take online surveys, access to broadband internet, and health literacy of terms used in items in the questionnaire.

Summary

This study aimed to describe the concepts of self-care diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes distress in non-Hispanic Black adults ages 18-64 years old living with T2DM in North Carolina. Additionally, the study aimed to ascertain if there are relationships between and among the concepts of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) and diabetes stress.

In this sample of non-Hispanic Black adults, the level of self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) was less than adequate, and the participants experienced moderate to high levels of diabetes distress. Income, last self-reported HbA1c, and the number of diabetes-related comorbidities showed a statistically significant association with self-care maintenance, self-care monitoring, and self-care management (with and without insulin use) scores. The total diabetes distress score showed a statistically significant association with self-care monitoring and self-care management (with and without insulin use). The diabetes distress subscales did not show a statistically significant association with the self-care of diabetes.

The findings demonstrated a positive association between total diabetes distress score and self-care monitoring and self-care management (with and without insulin use), indicating that as diabetes distress increases, so does the engagement in self-care of diabetes. Previous studies showed as diabetes distress increased, diabetes self-care behaviors decreased, contributing to poor glycemic control and poorer health outcomes. The findings indicate the need for more studies to examine the relationship between self-care of diabetes and diabetes distress in non-Hispanic Black adults living with type 2 diabetes.

Understanding the relationship between diabetes distress and the self-care of diabetes (self-care maintenance, self-care monitoring, and self-care management) is crucial in addressing the diabetes-related complications leading to poorer health outcomes in this population. Knowledge about the level of self-care of diabetes and diabetes distress was gained about non-Hispanic Black adults ages 18-64 with type 2 diabetes living in North Carolina. The findings of this study will inform clinical practice, education, recruitment strategies, and future research for this population.

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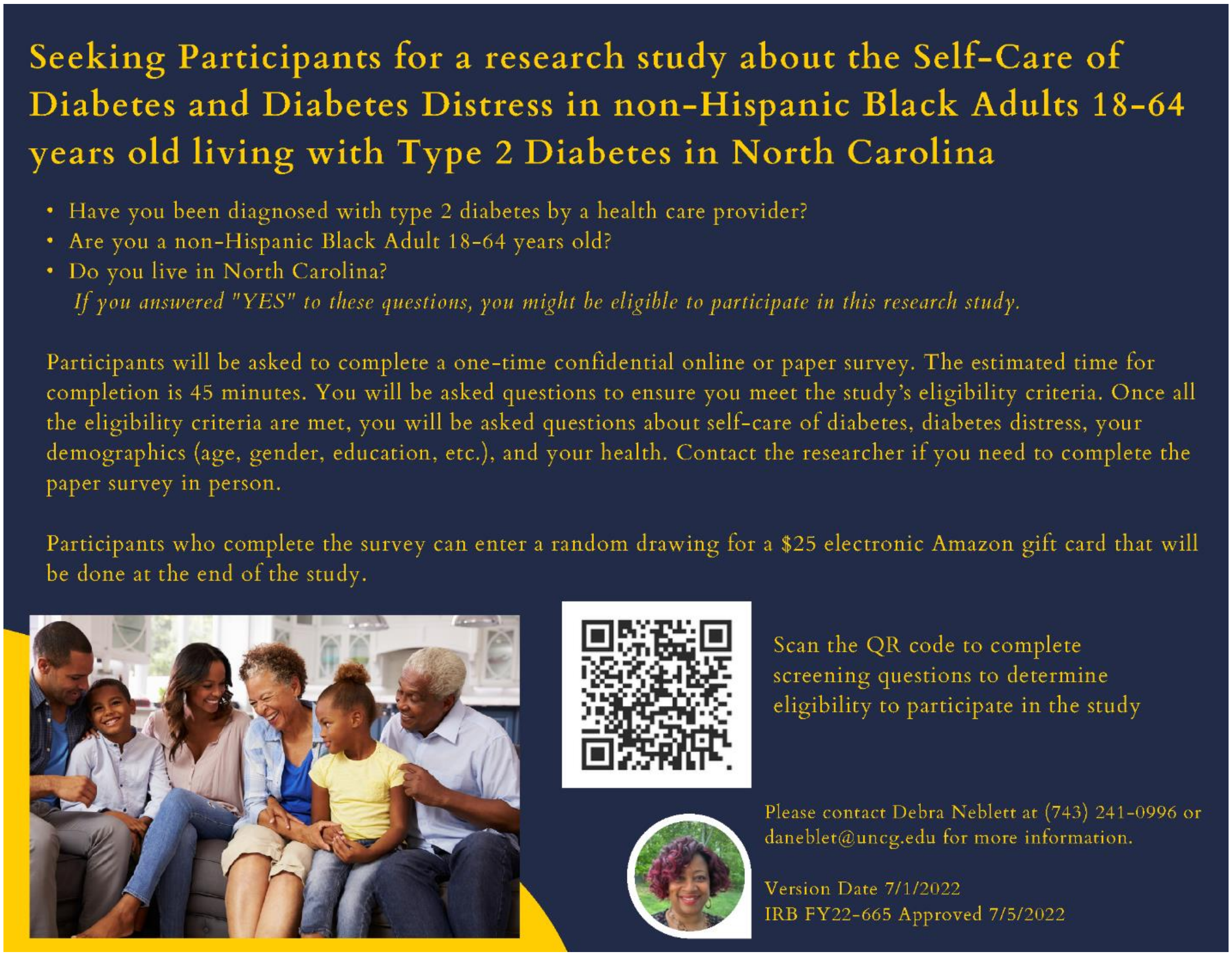
APPENDIX A: RECRUITMENT MATERIALS



Seeking Participants for a research study about the Self-Care of Diabetes and Diabetes Distress in non-Hispanic Black Adults 18-64 years old living with Type 2 Diabetes in North Carolina

- Have you been diagnosed with type 2 diabetes by a health care provider?
- Are you a non-Hispanic Black Adult 18-64 years old?
- Do you live in North Carolina?

If you answered "YES" to these questions, you might be eligible to participate in this research study.

Participants will be asked to complete a one-time confidential online or paper survey. The estimated time for completion is 45 minutes. You will be asked questions to ensure you meet the study's eligibility criteria. Once all the eligibility criteria are met, you will be asked questions about self-care of diabetes, diabetes distress, your demographics (age, gender, education, etc.), and your health. Contact the researcher if you need to complete the paper survey in person.

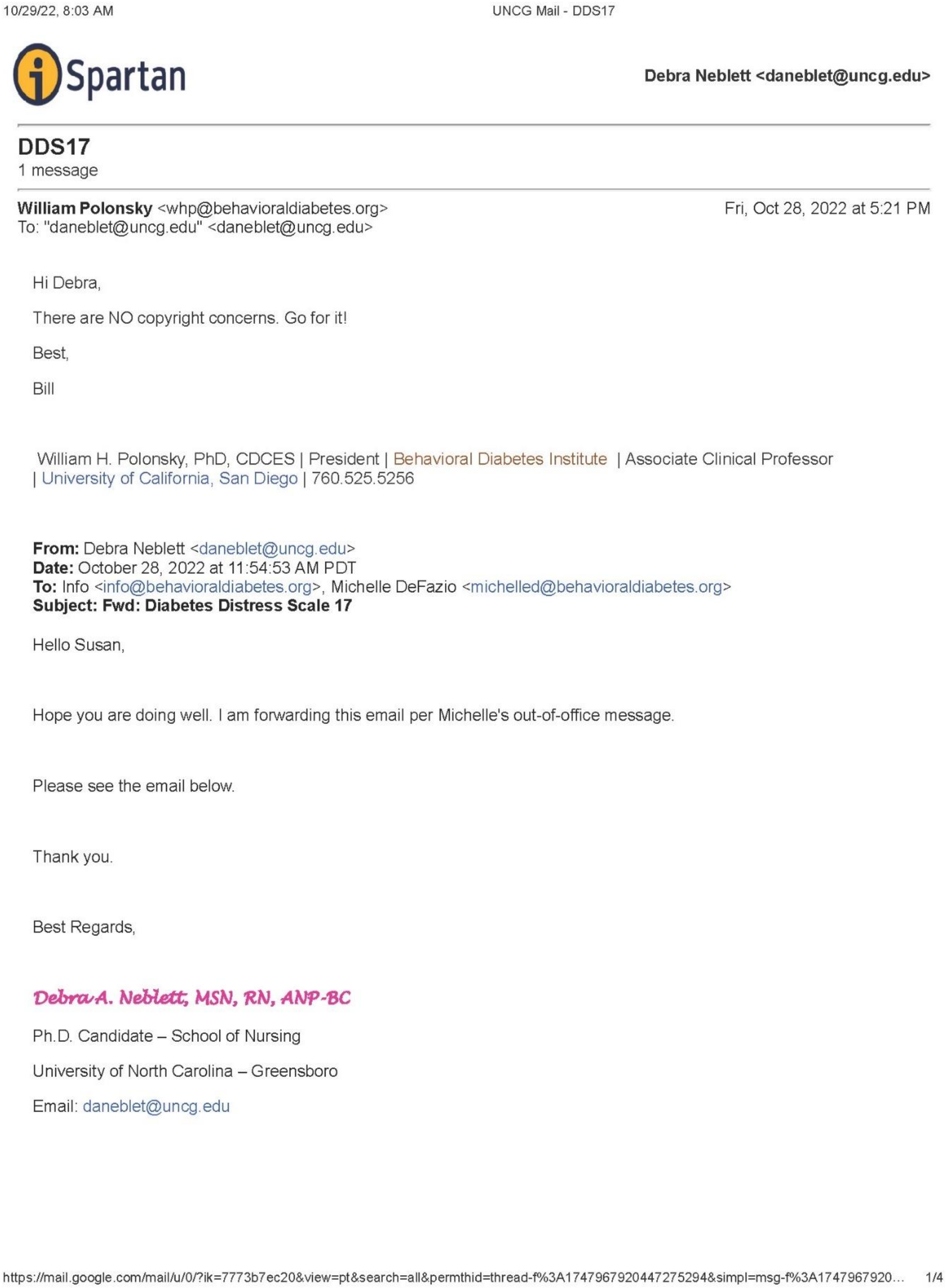
Participants who complete the survey can enter a random drawing for a $25 electronic Amazon gift card that will be done at the end of the study.

Scan the QR code to complete screening questions to determine eligibility to participate in the study

Please contact Debra Neblett at (743) 241-0996 or daneblet@uncg.edu for more information.

Version Date 7/1/2022
IRB FY22-665 Approved 7/5/2022

APPENDIX B: PERMISSIONS



10/29/22, 8:03 AM UNCG Mail - DDS17

Debra Neblett <daneblet@uncg.edu>

DDS17
1 message

William Polonsky <whp@behavioraldiabetes.org> Fri, Oct 28, 2022 at 5:21 PM
To: "daneblet@uncg.edu" <daneblet@uncg.edu>

Hi Debra,

There are NO copyright concerns. Go for it!

Best,

Bill

William H. Polonsky, PhD, CDCES | President | Behavioral Diabetes Institute | Associate Clinical Professor | University of California, San Diego | 760.525.5256

From: Debra Neblett <daneblet@uncg.edu>
Date: October 28, 2022 at 11:54:53 AM PDT
To: Info <info@behavioraldiabetes.org>, Michelle DeFazio <michelled@behavioraldiabetes.org>
Subject: Fwd: Diabetes Distress Scale 17

Hello Susan,

Hope you are doing well. I am forwarding this email per Michelle's out-of-office message.

Please see the email below.

Thank you.

Best Regards,

Debra A. Neblett, MSN, RN, ANP-BC

Ph.D. Candidate – School of Nursing

University of North Carolina – Greensboro

Email: daneblet@uncg.edu

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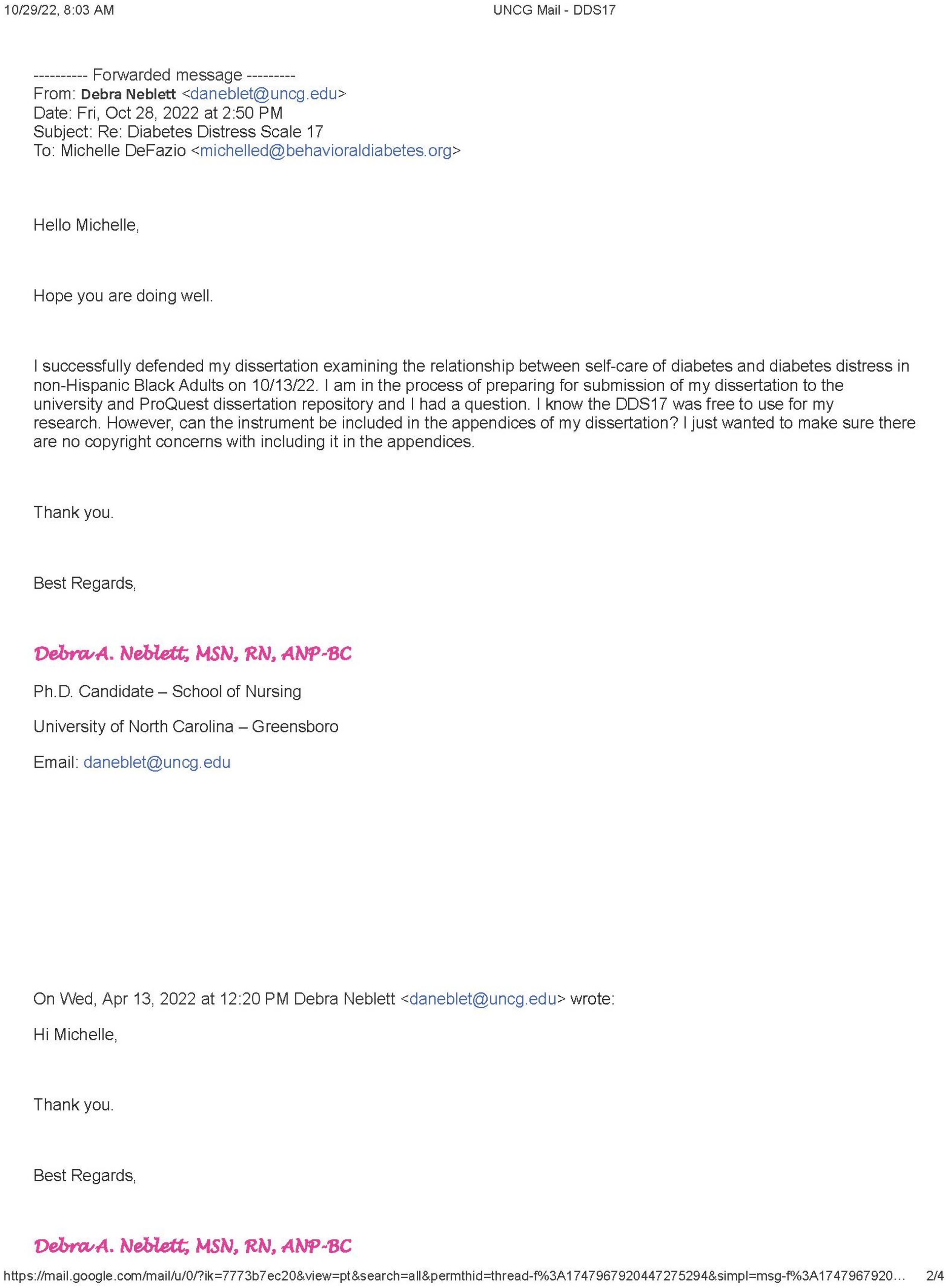


---------- Forwarded message ---------
From: **Debra Neblett** <daneblet@uncg.edu>
Date: Fri, Oct 28, 2022 at 2:50 PM
Subject: Re: Diabetes Distress Scale 17
To: Michelle DeFazio <michelled@behavioraldiabetes.org>

Hello Michelle,

Hope you are doing well.

I successfully defended my dissertation examining the relationship between self-care of diabetes and diabetes distress in non-Hispanic Black Adults on 10/13/22. I am in the process of preparing for submission of my dissertation to the university and ProQuest dissertation repository and I had a question. I know the DDS17 was free to use for my research. However, can the instrument be included in the appendices of my dissertation? I just wanted to make sure there are no copyright concerns with including it in the appendices.

Thank you.

Best Regards,

Debra A. Neblett, MSN, RN, ANP-BC

Ph.D. Candidate – School of Nursing

University of North Carolina – Greensboro

Email: daneblet@uncg.edu

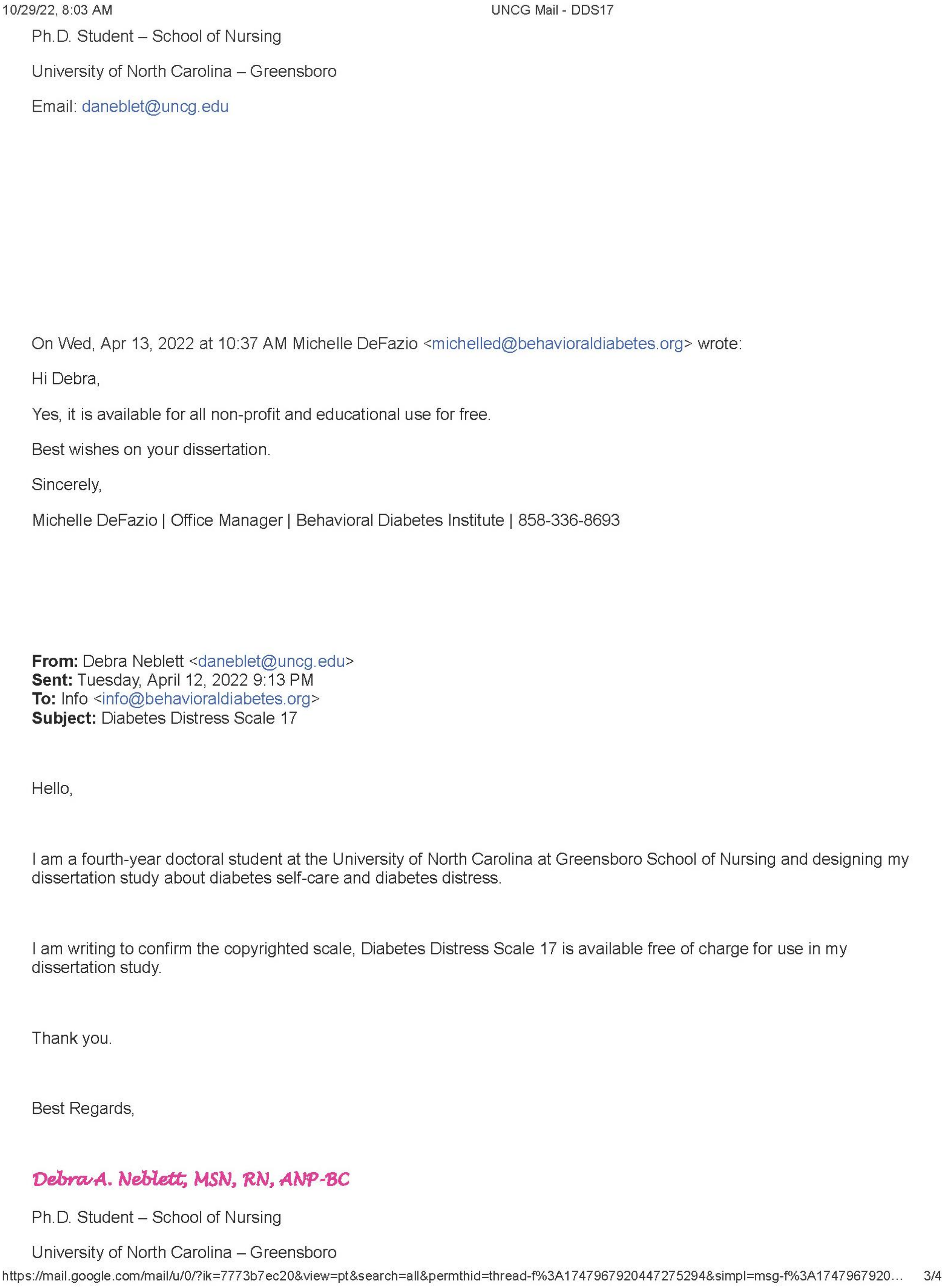
On Wed, Apr 13, 2022 at 12:20 PM Debra Neblett <daneblet@uncg.edu> wrote:

Hi Michelle,

Thank you.

Best Regards,

Debra A. Neblett, MSN, RN, ANP-BC



Ph.D. Student – School of Nursing

University of North Carolina – Greensboro

Email: daneblet@uncg.edu

On Wed, Apr 13, 2022 at 10:37 AM Michelle DeFazio <michelled@behavioraldiabetes.org> wrote:

Hi Debra,

Yes, it is available for all non-profit and educational use for free.

Best wishes on your dissertation.

Sincerely,

Michelle DeFazio | Office Manager | Behavioral Diabetes Institute | 858-336-8693

From: Debra Neblett <daneblet@uncg.edu>
Sent: Tuesday, April 12, 2022 9:13 PM
To: Info <info@behavioraldiabetes.org>
Subject: Diabetes Distress Scale 17

Hello,

I am a fourth-year doctoral student at the University of North Carolina at Greensboro School of Nursing and designing my dissertation study about diabetes self-care and diabetes distress.

I am writing to confirm the copyrighted scale, Diabetes Distress Scale 17 is available free of charge for use in my dissertation study.

Thank you.

Best Regards,

Debra A. Neblett, MSN, RN, ANP-BC

Ph.D. Student – School of Nursing

University of North Carolina – Greensboro

Spartan

Debra Neblett <daneblet@uncg.edu>

Your Request to Wolters Kluwer Health, Inc. Has Been Denied

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no-reply@copyright.com <no-reply@copyright.com> Fri, May 27, 2022 at 12:25 PM
To: daneblet@uncg.edu

Copyright Clearance Center

Dear Ms. Debra Neblett,

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Jul 13, 2022

This Agreement between Ms. Debra Neblett ("You") and Wolters Kluwer Health, Inc. ("Wolters Kluwer Health, Inc.") consists of your license details and the terms and conditions provided by Wolters Kluwer Health, Inc. and Copyright Clearance Center.

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Format	Print and electronic
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Portion	Figures/tables/illustrations
Number of figures/tables/illustrations	1
Author of this Wolters Kluwer article	No
Will you be translating?	No
Intend to modify/change the content	No
Title	The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes
Institution name	University of North Carolina at Greensboro
Expected presentation date	Dec 2022
Portions	Figure 2. Self-care maintenance, self-care monitoring, and self-care management are core elements of the self-care of chronic illness, pg 199
Requestor Location	201 Falcon Rd. 201 Falcon Rd. GIBSONVILLE, NC 27249 United States Attn: Debra Neblett
Publisher Tax ID	13-2932696

APPENDIX C: INSTRUMENTS AND SURVEYS

The Self-care of Diabetes Inventory (SCODI or "Scotty") was developed by a team in Italy based on the *Self-Care of Chronic Illness Theory*. They developed 40 SCODI items (5 points Likert type) utilizing clinical recommendations. They grouped them into four dimensions: self-care maintenance, self-care monitoring, self-care management, and self-care confidence based on the theory. SCODI can be accessed via http://self-care-measures.com/available-self-care-measures/self-care-of-diabetes-inventory/.

Developer's Primary Contact:
Davide Ausili, PhD, RN
Assistant Professor
Università degliStudi di Milano –Bicocca,
Via Cadore 48, Monza –Italy
Phone: +390264488032
Email: davide.ausili@unimib.it

Survey Questions for Self-Care of Diabetes and Diabetes Distress Research Study

---

Start of Block: STUDY INFORMATION SHEET BLOCK 1

Study Information Sheet

Please read the following information about the research study. Then you will complete screening questions to determine if you meet the study's criteria. If you meet the study's criteria, then you will proceed to the study's survey questions.

Title of the Research Study: The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes

Principal Investigator: Debra A. Neblett, MSN, RN, ANP-BC

Faculty Advisor: Dr. Laurie Kennedy-Malone

What is this all about?
You are invited to participate in this research study to examine the relationship between Self-Care of Diabetes and Diabetes Distress in non-Hispanic Black Adults 18-64 years old living with Type 2 Diabetes in North Carolina. Your participation in this research study is voluntary.

Participants will be asked to complete a one-time confidential online survey. The estimated time for completion is 45 minutes. You will be asked questions to ensure you meet the study's eligibility criteria. Once all the eligibility criteria are met, you will be asked questions about self-care of diabetes, diabetes distress, your demographics (age, gender, education, etc.), and your health.

How will this negatively affect me?
There are minimal physical or emotional risks associated with completing the one-time online or paper survey for the study.

What do I get out of this research project?
There may be potential indirect benefits to participants with exposure to the activities of self-care of diabetes and diabetes distress by increasing awareness about these concepts in

individuals living with diabetes.

Will I get paid for participating?

Participants will not be paid. But participants who complete the survey can enter a random drawing for a $25 electronic Amazon gift card that will be done at the end of the study.

What about my confidentiality?

All information collected as part of this study will be kept confidential. Participant confidentiality will be maintained using a three-digit identification number (starting at #001) on all data collection forms for the paper survey. All data collected from the online survey will be exported into the statistical program, and all data collected from the paper survey will be entered and the statistical program using an assigned three-digit identification number. All data collection forms will be stored in a locked file cabinet in the PI's home. All electronic data will be stored in Box per UNCG ITS recommendations which is more secure than a password-protected computer.

What if I do not want to be in this research study?

Your participation in this research study is voluntary. You can decide to withdraw from this research study at any time without penalty.

What if I have questions?

If you have questions and need information about the research study, please contact Debra Neblett at daneblet@uncg.edu or (743) 241-0996. You may also contact my faculty advisor, Dr. Laurie Kennedy-Malone, at lmkenne2@uncg.edu if you have any questions about this research.

If you have questions about your rights as a research participant or would like to discuss any concerns about this study with someone other than the researcher, please get in touch with the Office of Research Integrity at ORI@uncg.edu.

After reading the information sheet, participants will provide their agreement to participate in the study by proceeding to the next page of the study's online survey.

End of Block: STUDY INFORMATION SHEET BLOCK 1

Start of Block: INTRO SCREENING QUESTIONS BLOCK 2

Study Eligibility Screening Questions

I appreciate your interest in participating in this research study. Please respond to the following questions to determine your eligibility to proceed with the study survey questions.

Do you self-identify as a non-Hispanic Black, African American, or Black Adult?

○ Yes

○ No

Page Break

Are you 18-64 years old?

○ Yes

○ No

Have you been diagnosed with type 2 diabetes by a health care provider (Nurse Practitioner, Physician, or Physician Assistant)?

○ Yes

○ No

Do you live in North Carolina?

○ Yes

○ No

Are you currently on dialysis or have you received a kidney transplant related to diabetes complications?

○ Yes

○ No

Have you had a lower extremity amputation related to diabetes complications?

○ Yes

○ No

Do you speak English fluently (easily)?

○ Yes

○ No

Do you read and understand English?

○ Yes

○ No

Have you been diagnosed with memory or cognitive (thinking) problems?

○ Yes

○ No

Are you currently pregnant?

○ Yes

○ No

End of Block: INTRO SCREENING QUESTIONS BLOCK 2

If participants do not meet the study's eligibility requirements, they will not be able to proceed. They will receive a message via Qualtrics or be told the same message if they take the paper version in person.

Sorry, you did not meet the eligibility of this study.

I appreciate your time and willingness to participate in the study.

Debra A. Neblett, MSN, RN, ANP-BC

Ph.D. Candidate - UNCG School of Nursing

Start of Block: DEMOGRAPHIC/CLINICAL QUESTIONS BLOCK 3

Introduction:

Sociodemographic and Clinical Characteristic Questions The following questions will ask about your sociodemographics (age, gender, education, etc.) and clinical characteristics (your health).

*

How many years old are you? Write in your response to the following fill-in-the-blank question(s).

____

Select your gender:

○ Male

○ Female

Select your marital status:

- ○ Single
- ○ Married
- ○ Separated
- ○ Divorced
- ○ Widowed
- ○ Partnered

Select your educational level completed:

- ○ Less than the 12th grade
- ○ High school graduate/GED (general education diploma)
- ○ Associate Degree
- ○ Bachelor's Degree
- ○ Master's Degree
- ○ Doctorate or Ph.D.

Select your household income range:

- ○ Less than $25,000
- ○ $25,000 to $49,999
- ○ $50,000 to $74,999
- ○ $75,000 to $99,999
- ○ $100,000 or greater
- ○ I prefer not to answer

Do you have health insurance (health coverage)?

- ○ Yes
- ○ No

Do you use online resources for diabetes information?

- ○ Yes
- ○ No

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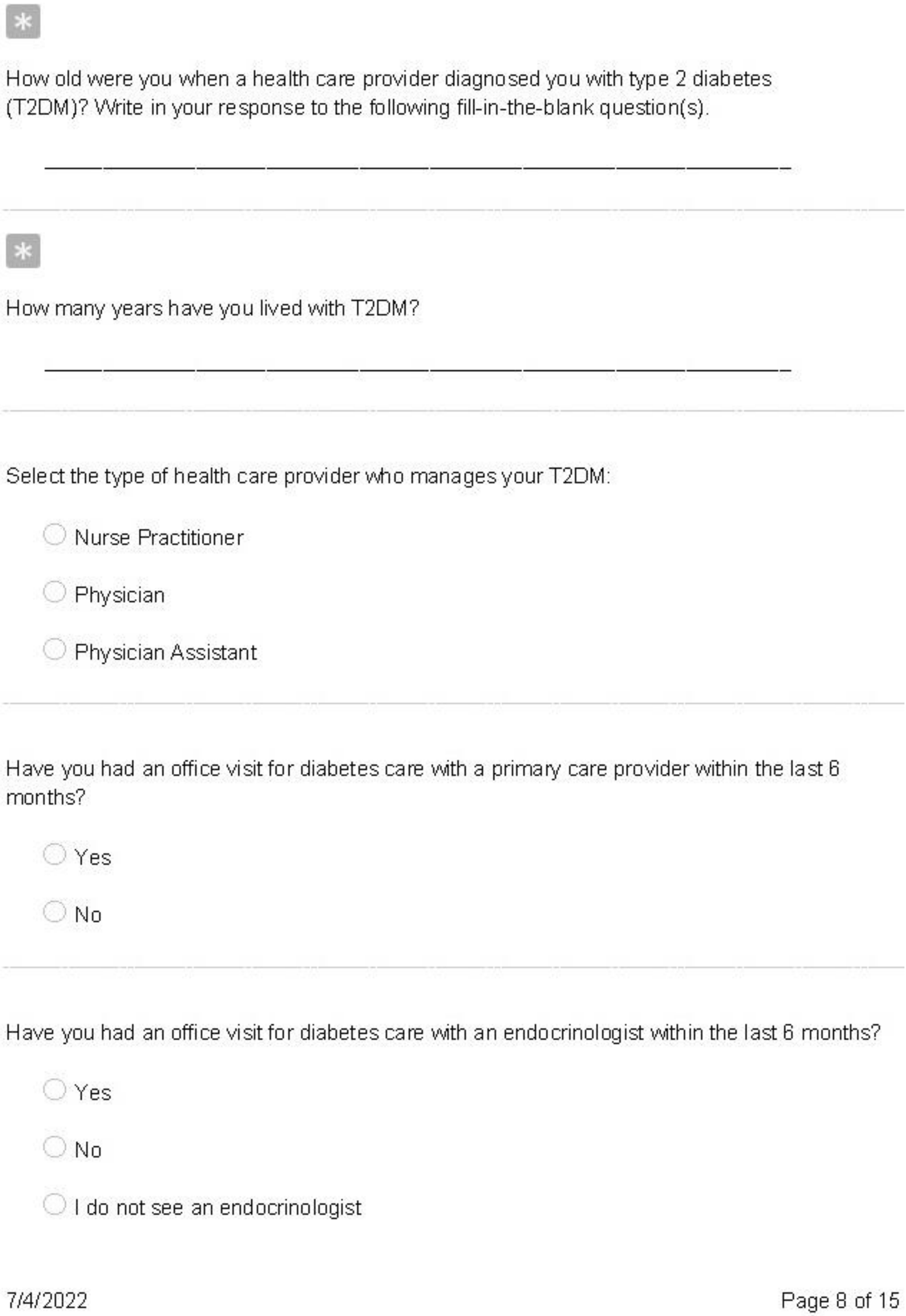


*

How old were you when a health care provider diagnosed you with type 2 diabetes (T2DM)? Write in your response to the following fill-in-the-blank question(s).

____

*

How many years have you lived with T2DM?

____

Select the type of health care provider who manages your T2DM:

○ Nurse Practitioner

○ Physician

○ Physician Assistant

Have you had an office visit for diabetes care with a primary care provider within the last 6 months?

○ Yes

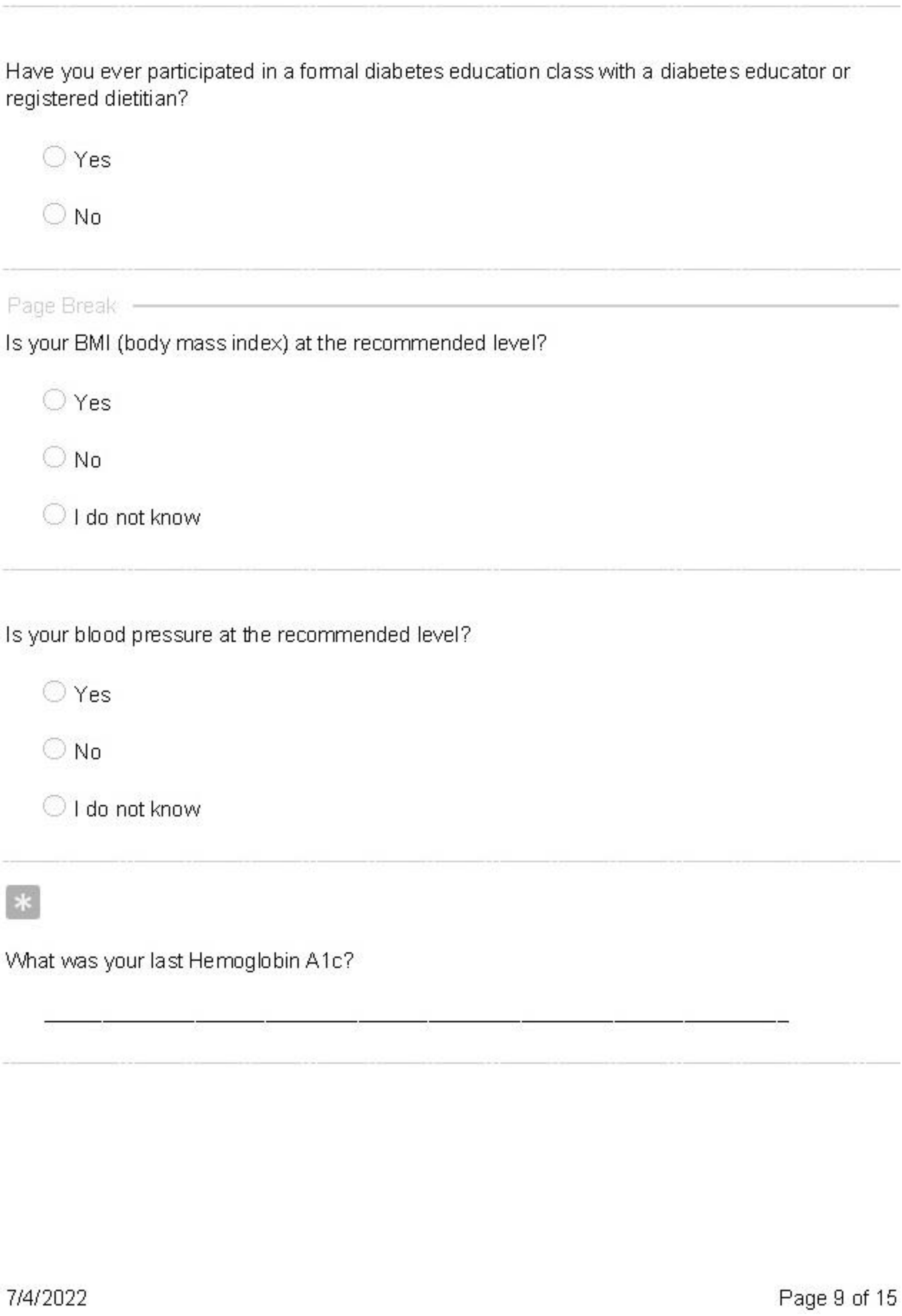
○ No

Have you had an office visit for diabetes care with an endocrinologist within the last 6 months?

○ Yes

○ No

○ I do not see an endocrinologist



Have you ever participated in a formal diabetes education class with a diabetes educator or registered dietitian?

○ Yes

○ No

Page Break

Is your BMI (body mass index) at the recommended level?

○ Yes

○ No

○ I do not know

Is your blood pressure at the recommended level?

○ Yes

○ No

○ I do not know

*

What was your last Hemoglobin A1c?

____

Is your Hemoglobin A1c at the recommended level?

○ Yes

○ No

○ I do not know

Do you take medication for the treatment of diabetes?

○ Yes

○ No

If YES, select the type of medication you take. Check all the boxes that apply:

☐ Oral medications (pills)

☐ Insulin injections (shots)

☐ Non-insulin injections (shots)

Check the box indicating the number of medications prescribed by your healthcare provider for the treatment of diabetes :

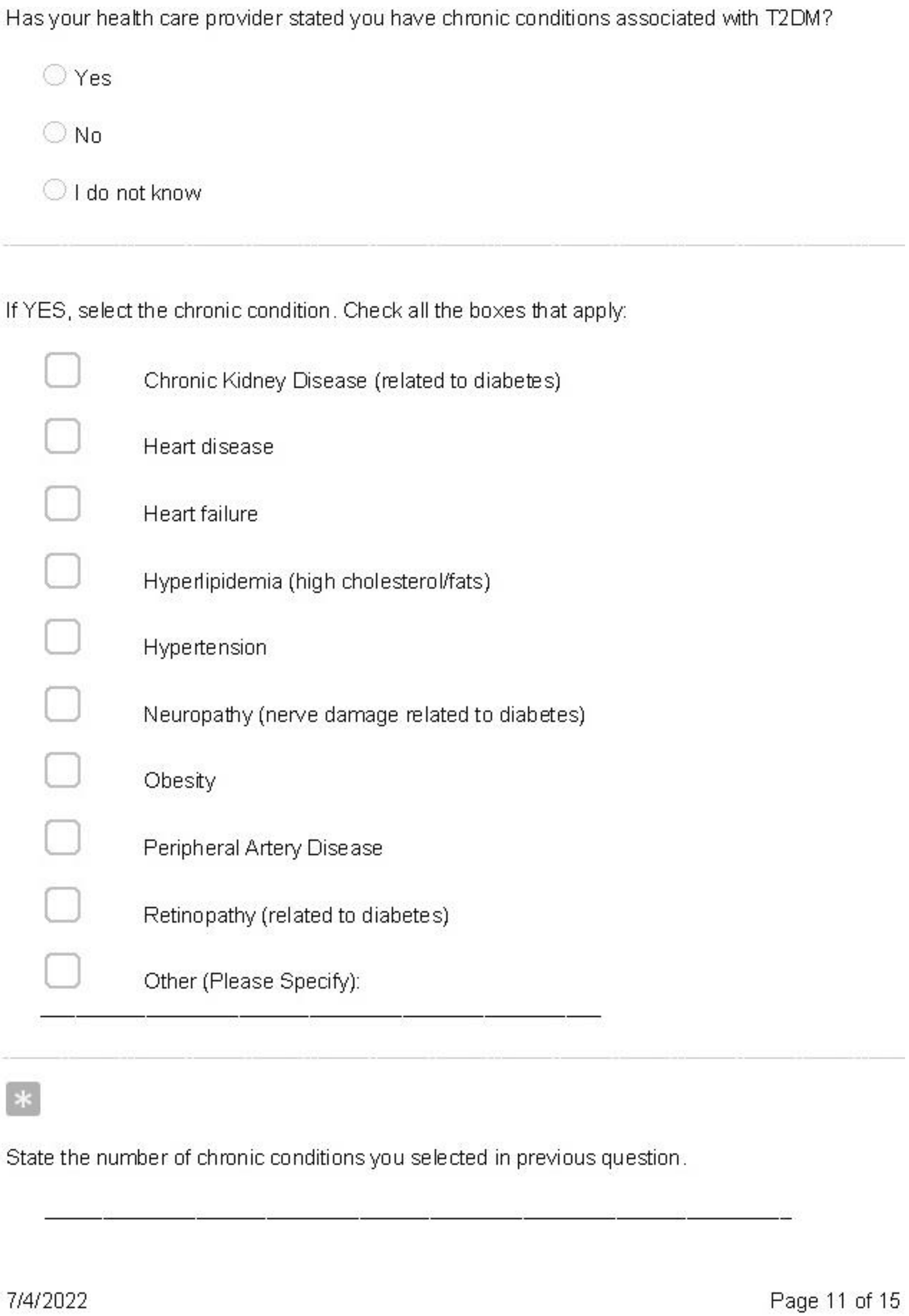
○ 0

○ 1-2

○ 3-4

○ More than 4

Page Break



Has your health care provider stated you have chronic conditions associated with T2DM?

○ Yes

○ No

○ I do not know

If YES, select the chronic condition. Check all the boxes that apply:

☐ Chronic Kidney Disease (related to diabetes)

☐ Heart disease

☐ Heart failure

☐ Hyperlipidemia (high cholesterol/fats)

☐ Hypertension

☐ Neuropathy (nerve damage related to diabetes)

☐ Obesity

☐ Peripheral Artery Disease

☐ Retinopathy (related to diabetes)

☐ Other (Please Specify): ______________________________

*

State the number of chronic conditions you selected in previous question.

____

Have you had any diabetes-related foot problems, ulcers, or infections?

○ Yes

○ No

Page Break

Do you have any of the following? Check all the boxes that apply:

☐ Family history of type 2 diabetes

☐ Personal history of gestational diabetes

☐ None

Do you feel you have support from others related to living with diabetes?

○ Yes

○ No

If YES, who do you identify as a support person? Check all the boxes that apply:

☐ Family

☐ Friends

☐ Health care provider

☐ Partner

☐ Spouse

☐ Other (Please specify):

____

Page Break

How did you learn about this research study?

- ○ Barbershop
- ○ Hair salon
- ○ Church
- ○ Flyers
- ○ Fraternity
- ○ Friend
- ○ Health care provider's office
- ○ Nail salon
- ○ Social media
- ○ Sorority
- ○ Word of mouth
- ○ Other (Please specify): ____

End of Block: DEMOGRAPHIC/CLINICAL QUESTIONS BLOCK 3

Start of Block: SCODI INSTRUMENT BLOCK 4

End of Block: SCODI INSTRUMENT BLOCK 4

Start of Block: DDS17 BLOCK 5

End of Block: DDS17 BLOCK 5

Start of Block: INCENTIVE QUESTION BLOCK 6

Participants completing the survey in its entirety, can choose to enter a random drawing for a $25 electronic Amazon gift card that will be done at the end of the study. If so, you will be be asked to provide an email or mobile number and taken to a separate survey from the study survey data which will protect your confidentiality. Qualtrics will randomly select respondents for $25 electronic Amazon gift cards.

Would you like to enter the random drawing for a $25 electronic Amazon gift card?

○ No

○ Yes

End of Block: INCENTIVE QUESTION BLOCK 6

End of survey message:

Thank you for completing the Survey Questions for the Study, "The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes".
Debra A. Neblett, MSN, RN, ANP-BC
Ph.D. Candidate - UNCG School of Nursing

Random Drawing for Self-Care of Diabetes and Diabetes Distress Research Study

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Start of Block: Incentive

Please provide your email or mobile number below to be entered into the random drawing for a $25 electronic Amazon gift card.

Random drawing will be done at the end of the study and participants randomly selected will receive it via the email or mobile number provided.

○ Email ____

○ Mobile number ____

End of Block: Incentive

End of survey message:

Thank you for completing the Survey Questions for the Study, "The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes".
Debra A. Neblett, MSN, RN, ANP-BC
Ph.D. Candidate - UNCG School of Nursing

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. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
4. Feeling angry, scared and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
6. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
7. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
8. Feeling that I am often failing with my diabetes routine.	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 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
10. Feeling that diabetes controls my life.	1	2	3	4	5	6
11. Feeling that my doctor doesn't take my concerns seriously enough.	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

DDS1.1 SCORING SHEET

INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress.[1] To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale.

Current research[2] suggests that a mean item score 2.0 – 2.9 should be considered 'moderate distress,' and a mean item score ≥ 3.0 should be considered 'high distress.' Current research also indicates that associations between DDS scores and behavioral management and biological variables (e.g., A1C) occur with DDS scores of ≥ 2.0. Clinicians may consider moderate or high distress worthy of clinical attention, depending on the clinical context.

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.

Total DDS Score:
a. Sum of 17 item scores. ______________
b. Divide by: _____17_______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

A. Emotional Burden:
a. Sum of 5 items (1, 4, 7, 10, 14) ________________
b. Divide by: _______5_______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

B. Physician Distress:
a. Sum of 4 items (2, 5, 11, 15) ______________
b. Divide by: _______4______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

C. Regimen Distress:
a. Sum of 5 items (6, 8, 3, 12, 16) ______________
b. Divide by: _______5______
c. Mean item score: ______________
Moderate distress or greater? (mean item score > 2) yes__ no__

D. Interpersonal Distress:
a. Sum of 3 items (9, 13, 17) ______________
b. Divide by: _______3______
c. Mean item score: ______________
Moderate distress or greater? (mean item score ≥ 2) yes__ no__

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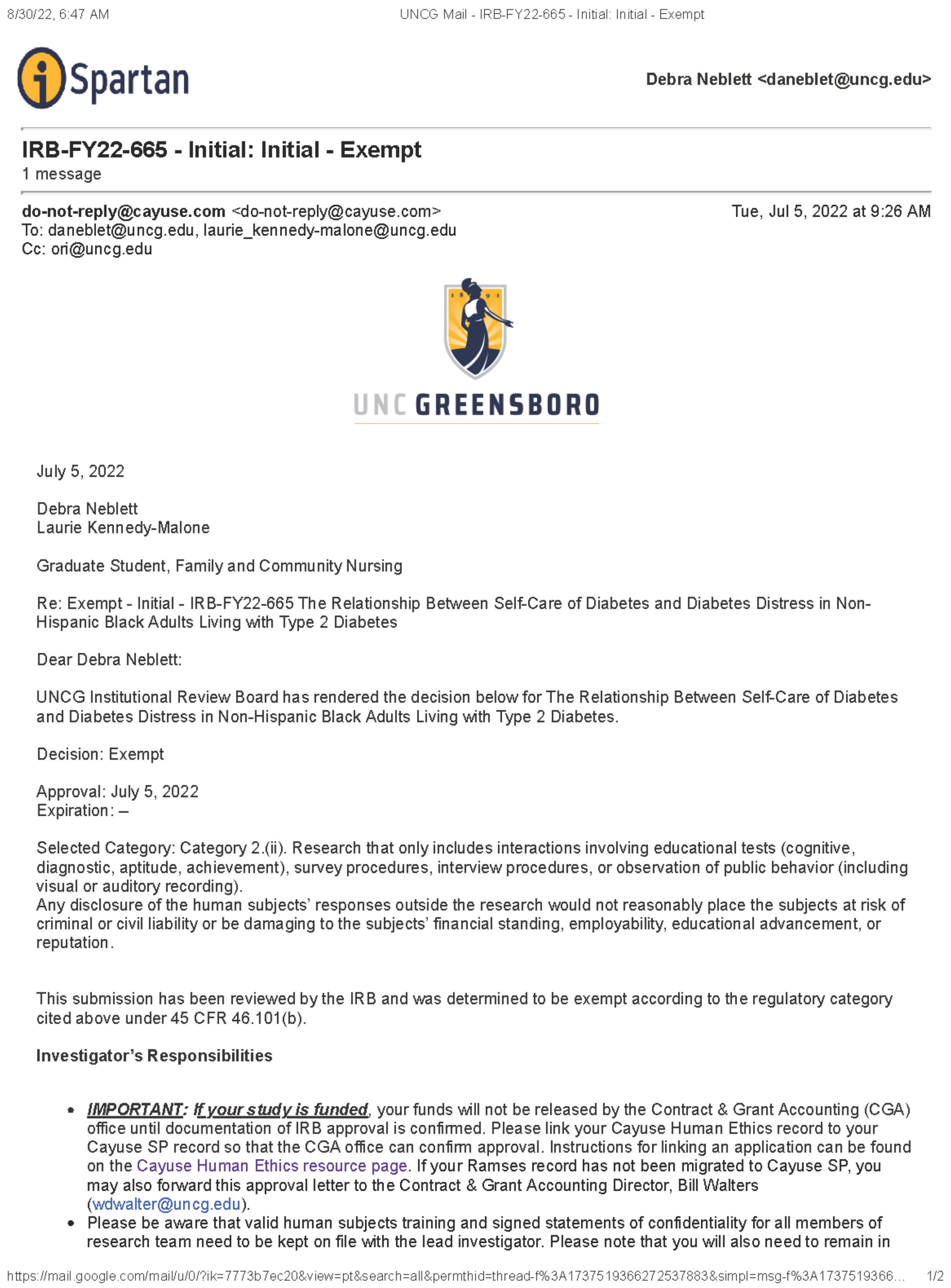
[1] Polonsky, W.H., Fisher, L., Esarles, J., Dudl, R.J., Lees, J., Mullan, J.T., Jackson, R. (2005). Assessing psychosocial distress in diabetes: Development of the Diabetes Distress Scale. Diabetes Care, 28, 626-631.

[2] Fisher, L., Hessler, D.M., Polonsky, W.H., Mullan, J. (2012). When is diabetes distress clinically meaningful? Establishing cut-points for the Diabetes Distress Scale. Diabetes Care, 35, 259-264.

APPENDIX D: STUDY APPROVAL AND INFORMATION SHEET



8/30/22, 6:47 AM UNCG Mail - IRB-FY22-665 - Initial: Initial - Exempt

Debra Neblett <daneblet@uncg.edu>

IRB-FY22-665 - Initial: Initial - Exempt

1 message

do-not-reply@cayuse.com <do-not-reply@cayuse.com> Tue, Jul 5, 2022 at 9:26 AM
To: daneblet@uncg.edu, laurie_kennedy-malone@uncg.edu
Cc: ori@uncg.edu

UNC GREENSBORO

July 5, 2022

Debra Neblett
Laurie Kennedy-Malone

Graduate Student, Family and Community Nursing

Re: Exempt - Initial - IRB-FY22-665 The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes

Dear Debra Neblett:

UNCG Institutional Review Board has rendered the decision below for The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes.

Decision: Exempt

Approval: July 5, 2022
Expiration: –

Selected Category: Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording).
Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.

This submission has been reviewed by the IRB and was determined to be exempt according to the regulatory category cited above under 45 CFR 46.101(b).

Investigator's Responsibilities

- ***IMPORTANT:* *If your study is funded***, your funds will not be released by the Contract & Grant Accounting (CGA) office until documentation of IRB approval is confirmed. Please link your Cayuse Human Ethics record to your Cayuse SP record so that the CGA office can confirm approval. Instructions for linking an application can be found on the Cayuse Human Ethics resource page. If your Ramses record has not been migrated to Cayuse SP, you may also forward this approval letter to the Contract & Grant Accounting Director, Bill Walters (wdwalter@uncg.edu).
- Please be aware that valid human subjects training and signed statements of confidentiality for all members of research team need to be kept on file with the lead investigator. Please note that you will also need to remain in

https://mail.google.com/mail/u/0/?ik=7773b7ec20&view=pt&search=all&permthid=thread-f%3A1737519366272537883&simpl=msg-f%3A1737519366… 1/2 compliance with the university "Access To and Retention of Research Data" Policy which can be found at http://policy.uncg.edu/university-policies/research_data/.

- **Please utilize the the consent form/information sheet with the most recent version date when enrolling participants.**
- Please be aware that any changes to your protocol must be reviewed by the IRB prior to being implemented.
- **If your study is funded**, please note that it is the responsibility of the Principal Investigator to link your IRB application to your Cayuse SP record.

Sincerely,

UNCG Institutional Review Board

Debra Neblett <daneblet@uncg.edu>

IRB-FY22-665 - Modification: Modification

1 message

do-not-reply@cayuse.com <do-not-reply@cayuse.com> Tue, Aug 2, 2022 at 9:26 AM
To: daneblet@uncg.edu, laurie_kennedy-malone@uncg.edu
Cc: ori@uncg.edu

August 2, 2022

Debra Neblett
Family and Community Nursing, Nursing

Re: Modification Approval - IRB-FY22-665 The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes

Dear Debra Neblett:

UNCG Institutional Review Board has rendered the decision below for The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes. This modification is now approved.

Decision: Exempt

- **Modification Information:** Submitted additional letters of support for participant recruitment sites

If this modification involved changes to the consent form/IRB Information Sheet, please utilize the the consent form/information sheet with the most recent version date when enrolling participants.

Sincerely,

UNCG Institutional Review Board

The University of North Carolina at Greensboro

Institutional Review Board (IRB) Information Sheet

Project Title: The Relationship Between Self-Care of Diabetes and Diabetes Distress in Non-Hispanic Black Adults Living with Type 2 Diabetes

Principal Investigator (PI): Debra A. Neblett, MSN, RN, ANP-BC

Faculty Advisor: Dr. Laurie Kennedy-Malone

What is this all about?

You are invited to participate in this research study to examine the relationship between Self-Care of Diabetes and Diabetes Distress in non-Hispanic Black Adults 18-64 years old living with Type 2 Diabetes in North Carolina. Your participation in this research study is voluntary.

Participants will be asked to complete a one-time confidential online or paper survey. You will be asked questions to ensure you meet the study's eligibility criteria. Once all the eligibility criteria are met, you will be asked questions about self-care of diabetes, diabetes distress, your demographics (age, gender, education, etc.), and your health. The estimated time for completion is 45 minutes.

How will this negatively affect me?

There are minimal physical or emotional risks associated with completing the online or paper survey for the study.

What do I get out of this research project?

There may be potential indirect benefits to participants with exposure to the activities of self-care of diabetes and diabetes distress by increasing awareness about these concepts in individuals living with diabetes.

Will I get paid for participating?

Participants will not be paid. But participants who complete the survey can enter a random drawing for a $25 electronic Amazon gift card that will be done at the end of the study.

What about my confidentiality?

All information collected as part of this study will be kept confidential. Participant confidentiality will be maintained using a three-digit identification number (starting at #001) on all data collection forms for the paper survey. All data collected from the online survey will be exported into the statistical program, and all data collected from the paper survey will be entered and the statistical program using an assigned three-digit identification number. All data collection forms will be stored in a locked file cabinet in the PI's home. All electronic data will be stored in Box per UNCG ITS recommendations which is more secure than a password-protected computer.

What if I do not want to be in this research study?
Your participation in this research study is voluntary. You can decide to withdraw from this research study at any time without penalty.

What if I have questions?
If you have questions and need information about the research study, please contact Debra Neblett at daneblet@uncg.edu or (743) 241-0996. You may also contact my faculty advisor, Dr. Laurie Kennedy-Malone, at lmkenne2@uncg.edu if you have any questions about this research.

If you have questions about your rights as a research participant or would like to discuss any concerns about this study with someone other than the researcher, please get in touch with the Office of Research Integrity at ORI@uncg.edu.

After reading the information sheet, participants will provide their agreement to participate in the study by proceeding to the next page of the online or paper survey for the study.