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Caregiver Status and Self-Reported Health Status Among African American

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This is to certify that the doctoral dissertation by

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Abstract

Caregiver Status and Self-Reported Health Status Among African American Women Suffering From Type 2 Diabetes

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MHSA, Strayer University, 2010

MBA, Strayer University, 2009

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

African American women (AAW) are at a high risk for type 2 diabetes, a debilitating and potentially fatal disease for which there is no cure. The purpose of this study was to extend the research of Mosca et al. (2012) by examining the relationship between caregiver status and self-reported health status for AAW 18 years or older diagnosed with type 2 diabetes. The chronic care model (CCM) provided the theoretical framework for this study. The CCM promoted routine care for patients with chronic illnesses to migrate from acute care to proactive, planned, and risk-based protocols. A binomial logistic regression investigated the relationship between caregiver status, categorized as paid or unpaid, and self-reported health status, which was dichotomized as either good to excellent health or poor to fair health. There was a statistically significant relationship between primary caregiver status and self-reported health status among AAW diagnosed with Type 2 diabetes after controlling for age, education, and marital status ($p < .004$). Based on the fitted binomial logistic regression model, there were 186 cases of AAW with type 2 diabetes; having a paid caregiver was associated with a lower odds of having good to excellent health (OR = 0.294). About 12.3% of the variance in self-report health status was attributable to caregiver status. Overall, 82.6% of predictions were accurate. Nearly all participants required frequent assistance from a caregiver in the preceding 12 months. These findings suggest a critical need for healthcare service providers to educate caregivers as a means to deliver post-acute care to AAW diagnosed with type 2 diabetes, consistent with the CCM.

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Dedication

To all my family members who have supported me through these difficult years. Words cannot express how much I love you all. Achieving this milestone would not have been possible without support from a network of people that love, care and encourage you when life and other things overwhelm you. To Cllr Karmo G. Soko Sackor, my husband, my best friend, my advisor, and my better half, for the encouragement and support through this tireless journey. To Alhaji Amara, Aminata, Zainab, Foday, and Amienata, our children, granddaughter and daughter- in-law, who have been supportive and understanding over the years. To Alhaji Amara Sackor and Hajah Mariama Gbatee Kaba Sackor, my lovely parents, for their support and prayers. To Fatumata Bamba Kaba, maternal grandmother, who encouraged me to obtain a Doctorate. To Hajah Matorgba Kaba Sackor, my aunt who has been very supportive over the years. To Mr./Mrs. Nelson Soko and Rebecca Suah who have encouraged me over the years. To all my siblings, and their families, for their unwavering support and understanding during this difficult journey.

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Chapter 1: Introduction to the Study

Background of the Study

Diabetes is the seventh leading cause of death in the United States, and it is estimated that 29.1 million people in the United States have all types of diabetes. These figures are anticipated to double by the year 2050 (American Diabetes Association [ADA], 2014; Centers for Disease Control and Prevention [CDC], 2014; Gumbs, 2012). Diabetes poses a serious financial burden on the nation. In 2012, the total estimated direct and indirect cost of diagnosed diabetes was $245 billion, $176 billion used for medical costs and $69 billion in reduced productivity. The new total showed that, there was a significant increase in diagnosed diabetes cost from the 2007 total estimated of $174 billion (ADA, 2008, 2014).

In the United States, the prevalence of diabetes in African Americans is significantly higher than Whites, Asian Americans, or Hispanics. Type 2 diabetes prevalence for non-Hispanic Blacks is 13.0 % compared to 15.9% for American Indians or Alaskan Natives, 12.8% for Hispanics, 9. 0% for Asian Americans, and 7.6% for non-Hispanic Whites (ADA, 2014; Kim, Berger & Matte, 2006). There is no cure for type 2 diabetes; proactive disease management significantly increases life expectancy and quality of life (ADA, 2008; Gumbs, 2012).

Effective glycemic control for individuals with type 2 diabetes requires insulin self-medication compliance, healthy eating habits, and regular physical activity (Montori & Fernandez-Balsells, 2009; Ross, Tildesley, &Ashkenas, 2011). Gene is a risk for poor glycemic control and diabetes-related complications. However, being overweight or obese significantly increases the risk of diabetes. Several studies found that supportive family members and caregivers were associated with better medication compliance, improved diet, and physical activities. Also, the quality and quantity of family caregiving significantly affects self-reported health (Dunbar, Clark, Quinn, Gary, & Kaslow, 2008).

Problem Statement

African American women (AAW) are at greater risk for diabetes than the general population and relative to non-Black women. Diabetes prevalence among AAW is 14.7% compared to 8.6% for the general population, and 6.5% for non-Hispanic White women. African American women comprise 13% of all American women and account for more than 50% of all new US type 2 diabetes annually (Gumbs, 2012).

According to Krishnan, Cozier, Rosenberg, and Palmer (2010), patient's socioeconomic status (SES) plays a significant role in the development and treatment plans for type 2 diabetes patients that may contribute to frequent hospitalizations and poor self-reported health among AAW diagnosed with type 2 diabetes. Also, there is a cultural tendency for low-SES AAW to subordinate their medical needs to the overall needs of the family (Mosca et al., 2012).

Low-SES family members frequently become the primary caregiving resource to encourage treatment compliance, which is problematic for AAW because they are most often the family caregiver. Family caregivers often assist the chronically ill with at least one of the following tasks: taking prescribed medications, walking, or monitoring medical treatment recommendations. This suggests caregivers could influence glycemic control and enhance clinical outcomes (Mosca et al., 2012).

Caregiver assistance can also be given in the form of instrumental tasks such as: taking medications, arranging visits to the doctor, transporting the patient to a doctor's visit, groceries shopping, preparing meals, and attending to medical needs (e.g. changing bandages) (Mosca et al., 2012).

Paradoxically, Mosca et al. (2012) reported a significant association between having a paid or unpaid caregiver and worse self-reported health for type 2 diabetes patients relative to patients with no caregiver. The caregiver and no caregiver distinction was also significant for other demographics; for individuals ages 65 years or older, members of a racial or ethnic minority group, those who lack health insurance, or have a history of diabetes mellitus or hypertension (Mosca et al., 2012). Additionally, caregiver and no caregiver distinction was associated with longer postoperative hospital length of stay among patients who underwent cardiac surgery. There is a gap in the literature regarding the relationship between type 2 diabetes, caregiver status, and self-reported health for AAW.

Purpose of the Study

The purpose of this study was to examine the relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after accounting for age, education, and marital status. The study addressed the gap in the literature regarding the relationship between caregiving status and self-reported health status for a sample of AAW diagnosed with type 2 diabetes. The study's contribution to society was to inform the process of designing disease management protocols to reflect AAW and cultural issues.

Research Question and Hypotheses

Is there a relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status?

H_o: There is no relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status.

H_{1a}: There is a relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after for age, education, and marital status.

Theoretical Framework

The chronic care model (CCM) provided the theoretical framework for this study. The CCM presents a structure for organizing health care to make better self-reported health among patients with chronic illness. Better self-reporting can be achieved by changing the routine care for patients with chronic illnesses from acute and reactive to proactive, planned, and population-based (Nolte & McKee, 2008). These goals can be attained through a combination of the four components of the CCM in the health system framework together with links to community-based programs. Proactive primary care disease management, family support, self-management support, and the availability of community resources form the foundation for addressing the diabetes epidemic.

There is no cure for type 2 diabetes, so disease management interventions are focused on promoting overall health and maximizing quality of life. Disease management includes: (a) integrating family members to act as unpaid caregivers in diabetes self-management activities, (b) educating caregivers to support compliance with diabetes care guidelines, and (c) providing case management to promote use of community resources that improve glycemic control.

A recent national study conducted in several major U.S. cities indicated that AAW continue to face significant barriers to health care access and are at greater risk of disease, compared with the general population living in the same geographical area (Baty, Viviano, Schiller, &Wendling, 2010; Liao et al., 2011).

Specifically, Liao et al. (2011) suggested that the utilization of preventive services by minority populations was poor because of a lack of knowledge as well as fear or distrust of the medical environment, among other cultural health related attitudes. Therefore, offering opportunities to integrate caregiver health interventions for chronic disease management in these communities was of greater importance for reducing the burden of the disease and the premature mortality rates among ethnic minorities due to disease-related complications. Integrating caregiver health intervention in this community was critical because diabetes care in older adults is complex and requires multidisciplinary approaches. In communities where long-term care is needed, positive changes included improved daily glycemic control, reduced ranges of glycated hemoglobin (HbA1C), and improved cholesterol (LDL) (Baty et al., 2010). Improvements in clinician performance, according to previous studies, suggest that an inclusion of comprehensive foot evaluations, referrals to specialists, and physical activity are all beneficial (Baty et al., 2010).

Nature of the Study

The study used a quantitative methodology to examine the relationship between caregiver status and self-reported health status for AAW diagnosed with type 2 diabetes. In a quantitative study, the hypotheses are either accepted or rejected based on observational results (Leedy & Ormrod, 2012). The use of quantitative methodology is appropriate when: (a) independent and dependent variables can be clearly defined and measured, (b) one or more research questions can be clearly articulated, and (c) high levels of reliability and validity are desired (Leedy & Ormrod, 2012).

A total of 186 participants completed three documents: (a) consent form, (b) self-report health status survey, and (c) caregiver status. Survey Monkey anonymized the data before delivery to the researcher, which provided the primary mechanism for participant confidentiality. The sample size was determined using the following powering information. Alpha was set at $\alpha = 0.05$ and $p < 0.05$ using two-tailed tests (Tabachnick & Fidell, 2001). A complete discussion of sample powering is contained in Chapter 3.

Definitions

Caregiver: A caregiver is defined as someone, either paid or unpaid, who assists a patient with medical and preventive care, and with daily activities and chores. The caregiver can be a family member, parent or friend, spouse or partner who provides care or assistance. Caregiver can also be a professional with training or expertise in providing care, such as a nurse or home aide, who assists in identifying, preventing or treating a disease, illness, or disability are also considered caregivers (Mosca et al., 2012).

Caregiver status: Caregiver status is the independent variable and is defined as follows:

1. An *unpaid caregiver* is a friend or family member that assists with medical and lifestyle therapy compliance, and or with daily living assistance
2. A *paid caregiver* is any professional caregiver providing a service associated with diabetes care and management (e.g., nurse/home aide), or
3. none (see Appendix C) (Mosca et al., 2012).

Exclusion Criteria: Participants that reported both a paid caregiver and a substantial unpaid caregiver were excluded from the study.

Self-reported health Status: The study dependent variable (Appendix B, Question 8). Self-reported health status was a good predictor of future disability, hospitalization, and mortality (Jamoom, Horner-Johnson, Suzuki, Andresen, & Campbell, 2008). Self-reported health status was based on the answer to Question 8 of the DCP (Appendix B) (CDC, 2012a). Study participants were divided into two groups based on the answers to Question 8. Group 1 contained participants that reported their overall health as excellent, very good, or good, and Group 2 included those who reported their overall health as fair or poor (CDC, 2012a).

Diabetes is a lifelong disease in which there are high levels of sugar in the blood due to improper use of insulin by the body. In the beginning, the pancreas makes extra insulin to make up for it. But over time the pancreas is unable to keep up and cannot make enough insulin to keep blood sugar at normal levels (ADA, 2014).

Assumptions

The study relied on the following assumptions:

1. The study sample recruited by Survey Monkey contained no systematic bias and fairly represents the underlying population of AAW diagnosed with type 2 diabetes and no longer working due to illness or retirement.
2. The study used a *ceteris paribus* assumption for all unmeasured variables to isolate variance attributable to the independent variables. The study assumed the relationship between caregiver status and self-report health status was not an artifact of an unmeasured covariate not contained in the study.

Delimitations

This dissertation was delimited to:

1. The evaluation of self-report health status for a sample of AAW diagnosed with type 2 diabetes and its relationship to having a paid or unpaid caregiver.
2. The evaluation of a single sample of AAW with type 2 diabetes and willing to participate in the study.

3. The evaluation of self-report health status for a sample of AAW diagnosed with type 2 diabetes and its relationship to having a paid or unpaid caregiver after accounting for age, education, and marital status

Limitations

There were three primary limitations to this research study to note. First, self-report health status questionnaires were relatively unreliable compared to hospital or lab records. Second, the sample was limited to AAW with type 2 diabetes who agreed to participate in SueveyMonkey Surveys. It is difficult to anticipate the type or extent of bias this sampling method might introduced, as such, the results did not generalize to the entire population of AAW. Third, the selection of a single measure of self-reported health status excluded other important measures of health and well-being.

Significance

This quantitative research study tested for an association between caregiver status and self-reported health status for AAW diagnosed with type 2 diabetes. The study has addressed a gap in the literature regarding the relationship between caregiving and self-reported health status for a sample of AAW diagnosed with type 2 diabetes. This study was important because it informed the process for determining an appropriate treatment protocol for AAW with type 2 diabetes to improve self-reported health status for AAW, an underserved population. The study made an original contribution to public health by identifying whether the presence of a caregiver affects self-reported health status for AAW with type 2 diabetes.

Public health leaders and policy makers could be empowered to make informed decisions and develop policies that target educational intervention to caregivers to improve self-reported health status, and reduce health care costs.

Summary

The study used a quantitative research design to examine the association between caregiver status and self-reported health status for a sample of AAW diagnosed with type 2 diabetes. The study used a convenience sample of 186 AAW drawn from Survey Monkey, a commercial survey company. Studies show a positive correlation between the presence of supportive caregivers and better self-reported health status. The study addressed a gap in the literature regarding AAW with type 2 diabetes, caregiver status and self-reported health status. I used the following outline.

Chapter 2 examines the CCM as it relates to caregivers and disease management, type 2 diabetes prevalence, treatments, and causes are presented in the context of the CCM. Research on diabetes disease management, caregivers, diabetes self-reported health status, and current type 2 diabetes treatment protocols are analyzed.

Chapter 3 describes the research design, methodology, data analysis plan, procedures, and ethical assurances.

Chapter 2: Literature Review

This literature review examined research related to diabetes prevalence among AAW, minority women's health, issues concerning glycemic control, disease management strategies indicators, clinical treatment principles, and caregiver interventions. Diabetes is a disease without a known cure and significant comorbidity rates with serious diseases, such as cardiovascular disease (CVD). The most common approaches to diabetes disease self-management are medication treatments, adherence to healthy eating habits, and maintaining a physical activity regimen as part of a lifestyle routine. This study attempted to expand the knowledge and understanding of the association between caregivers, glycemic control, and self-reported health status for a population of AAW.

Literature Search Strategy

The literature included searches of the following online databases for books, periodicals, and scholarly journals: EBSCOhost, ERIC, Google Scholar, ProQuest, PubMed, Sage, and JSTOR. The following diabetes-related websites were searched: American Diabetes Association, Center for Disease Control and Prevention (CDC), Center for Science in the Public Interest (CSPI), McKinsey & Company, National Institute of Health (NIH), Robert Wood Johnson Foundation (RWJF), Trust for America's Health (TAH), and United States Census Bureau. The Google search engine was employed for all searches except when individual sites or databases used other applications.

Keyword and key search terms identification was an iterative process. The following keywords were searched initially: *caregiver status, caregiver status and diabetes, caregiver status and African American women, diabetes, diabetes management, diabetes, and African American women, caregiver status and diabetes, chronic care model, model of disease management, diabetes management and race, and disease management and gender*. Additional keywords and key search terms were developed from this initial group.

Sources included in the literature review included journal articles, scholarly books, published dissertations, periodicals, medical websites, and insurance regulations. The literature reviewed the years 2000 to 2014 and drew on some earlier works for the theoretical framework and history. The literature review included 103 separate works of which 66 were quantitative studies, and the balance were qualitative or theoretical. Eighty- three works were directly referenced and were cited.

Theoretical Framework

Chronic Care Model

The chronic care model (CCM) provided the theoretical framework for studying the association between caregiver status and self-reported health status for those diagnoses with type 2 diabetes. The CCM was a highly structured approach to daily disease management to improve self-reported health status by closely managing routine patient care in a planned, proactive, and population-based manner, rather than the current episodic, reactive care to acute conditions (Nolte & McKee, 2008). The CCM suggested that medication self-management, adherence to healthy eating habits, and a lifestyle including routine physical activity or exercise. The chronic care mode was an appropriate framework for this study because it incorporates a significant caregiver role in chronic disease management.

Disease management protocols for type 2 diabetes suggest an important role for paid and unpaid caregivers in the day-to-day patient care. Interventions include: (a) educating family members on daily self-management activities, (b) integrating family members into daily self-management as unpaid caregivers, and (c) encouraging caregivers to identify available community resources. The literature review included a discussion of the CCM theoretical framework, the prevalence of type 2 diabetes and the effect of caregivers on self-reported health status.

The chronic care model was developed to improve self-reported health status for the 90% of chronically ill patients in the United States who receive treatment in a primary care setting. The goal of the CCM was to create informed, involved patients, combined with a prepared and a proactive primary care practice team working together to improve health outcomes. The model integrates several healthcare delivery elements to foster productive interactions between patients and primary care providers (See Figure 1).

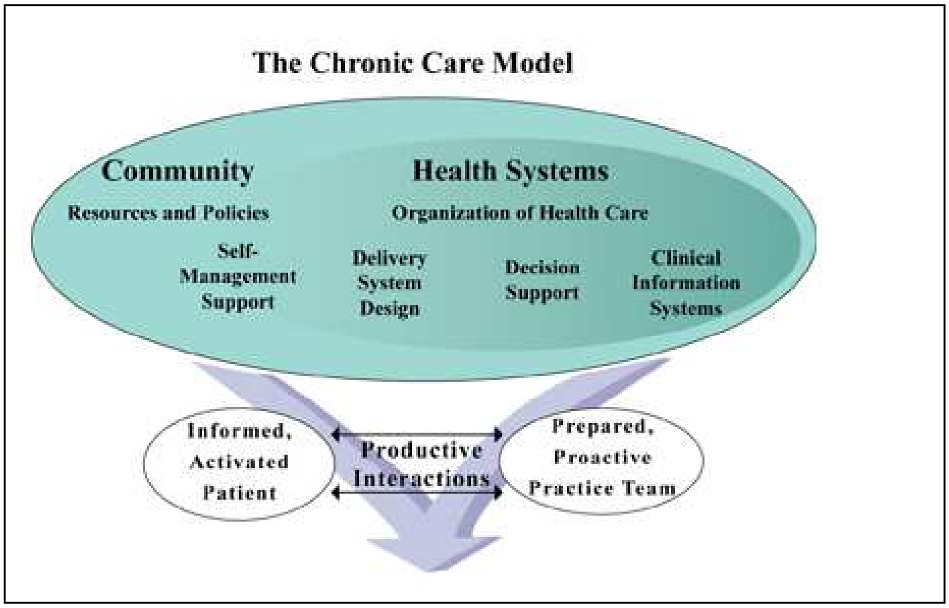


Figure 1. Chronic care model (RWJF, 2009, p. 23).

In a study conducted by Wagner et, al. (2008), Dr. Wagner suggested that the current health delivery system is antiquated because it failed to make the shift from an acute-care, infectious model to chronic disease management. The CCM is intended to promote the transition away from the current acute care, problem-based model toward chronic, long-term care management. The CCM is being implemented in more than 300 diverse U.S. healthcare systems to improve the quality of care for asthma, congestive heart failure, depression, and diabetes. Researchers have suggested that the CCM improved healthcare outcomes for a variety of different organizations, including primary care offices and the Veteran’s Administration (Wagner et al., 2008).

The CCM identified and organized protocol changes expected to improve chronic illness care. Chronic care delivery occurs in three overlapping circles: “the entire community including resources and policies, the health care system including its payment structures, and provider organization" (Wagner et al., 2008 p.69). The chronic care model identified six essential elements for providing high-quality care to patients with chronic illnesses: *delivery system design, self-management support, decision support, clinical information systems, community resources, and health system organization*. These six elements were a blueprint for chronic care that was evidence-based, population-based, and patient-centered (Wagner et al., 2008).

The CCM is an ideal model to implement for improving diabetes-related self-reported health and preventing the long-term complications of diabetes. Each CCM element manifests itself in diabetes disease management. The CCM encourages diabetes education classes, *diabetes days* at the primary care provider's office, patient self-management programs, and enhancement to existing clinical information systems for continuing staff education (Wagner et al., 2008).

Health System Organization

The Institute of Medicine (IOM) developed a set of basic concepts to guide disease management in general. Each concept was presented here as it related to diabetes disease management (Simmons et al., 2009). Diabetes disease management was an evidence-based clinical protocol, which adhered to guidelines promulgated by the American Diabetes Association (ADA). The protocol employed a team approach that included doctors, nurses, educators, and dietitians in a patient-centric delivery model. Access to diabetes self-management education (DMSE) for the patient, family, and caregivers was a priority (Whittemore, & Dixon, 2008).

Finally, clinical information systems were necessary, including patient registries, applications, and reminders. Unfortunately, the IOM guidelines currently represented the ideal rather than the common practices. The current paradigm is not evidence-based, but experience and training based. Primary care is physician centric, who often does not see the patient as the primary care giver to be empowered with self-management knowledge, skills, and support. Insurance companies limited access to diabetes specialists, and primary care was fragmented and acute needs focused (Simmons et al., 2009).

In an effort to reduce the fragmentation of healthcare delivery in the United States, (Hass et al., 2012) made the following recommendations:

1. Care is delivered through a consistent healing relationships.
2. Care is customized based on patient needs, culture, and values.
3. The patient is the source of control.
4. Knowledge or information is shared.
5. Decisions are evidence based.
6. Safety is paramount.

Three of these rules were directly applicable to diabetes care and management and should comprise a part of any diabetes disease management protocol (Haas et. al, 2012; Whittemore, & Dixon, 2008).

Clinical Information Systems

Effective chronic illness care required a comprehensive web-based clinical information system for tracking and monitoring treatment compliance (Simmons et al., 2009). A clinical information system enabled automated compliance reminders using texts, email, and diary applications to promote compliance and plan care. Web-based application monitored the progress of specific populations, measured quality improvements and created the data needed to adjust interventions, which was critical to effective chronic disease management in the private setting (Tsai et al., 2005).

Clinical information systems need not be complex. Initially, compliance tracking, and web-based patient and family education created an entry point for all stakeholders. The clinical information system had a minimum of three functions. First, it was a registry for planning individual care and conducting population-based monitoring and reporting. Second, it managed schedules and sent automated text or email reminders to patients and primary care teams to improve compliance. Third, it provided population-wide metrics on key performance metrics, such as A1C and lipid levels (Tsai et al., 2005).

Patient information, test results, protocols, compliance, and outcome data were captured in a web-based database or registry. The database used by care management applications was a necessary predictor for efficient healthcare using disease management based applications (Liao, 2011). The use of a registry gave healthcare providers the ability to track, monitor, and provide feedback on interventions and outcomes. Registries and applications enabled healthcare providers to proactively remind patients of their responsibilities for self-management rather than waiting for them to be present for care. Registries efficiently automate the delivery of recurring, planned care without placing incremental demands on the time of the private healthcare team (Tsai et al., 2005).

A significant body of research indicated that a clinical reminder application increases the frequency of preventive procedures and promoted disease self-management compliant behavior in patients (Liao, 2011). While diabetes-related conditions were not included in the study, cardiovascular risk reduction reminders have similar protocols as diabetes, such as blood pressure check, blood pressure tests, and cholesterol screening (Bodenheimer, & Laing, 2007).

Decision Support

Consistent and universal application of disease management practices is necessary to maximize healthcare outcomes. Treatment decisions should follow clinical research supported guidelines, such as the American Diabetes Association Standards of Care (ADASC); the Diabetes Quality Improvement Project (DQIP) measures; the American Association of Clinical Endocrinologist's (AACE); Medical Guidelines for the Management of Diabetes Mellitus, and the National Standards for Diabetes Self-Management Education (NSDSME). Patient education should include a discussion of the science supporting the treatment plan to internalize the rules and promote compliance (Tsai et al., 2005).

The CCM promoted collaborative care, or the introduction of specialist expertise into the primary care setting. Collaborative care was particularly important for treating the complexity of diabetes disease. A study of primary care providers revealed that most believed they were inadequately trained or prepared to meet the psychosocial and educational needs of diabetes patients. They reported that diabetes was difficult to treat relative to other chronic diseases, due to comorbidity and coordination of care. Collaborative care delivered comprehensive care in the primary care setting and created opportunities for cross learning (Bodenheimer, & Laing, 2007).

Delivery System Design

The CCM sought to transition chronic care management from a reactive system, initiating action only when a patient presented with an acute issue, to a proactive system, which was communicating real-time preventive care reminders to patients and primary care staff. For diabetes in particular, healthcare included proactive, efficient clinical care and self-management support. The system design reflected the diagnosis, roles and responsibilities for care management, time-based structured care, and a best practices algorithm to consistently deliver the best care available (Whittemore, & Dixon, 2008).

Automated follow-up and reminders were part of the standard procedure to promote self-management after the acute episode passed. Effective chronic disease management required more than adjusting the existing primary care delivery system, the best self-reported health status arose from automated systems to maintain regular contact, improve follow-up compliance, collect critical data on health and disease status, and meet educational and psychosocial needs (Liao, 2011).

Community Resources

Community resources, partnerships, policies, and collaborations can leverage patient and primary care resources to improve self-reported health for patients with chronic conditions. Local community centers, county and state departments of health, and national patient organizations represent the incremental capacity for the local health system's care for chronically ill patients. The CCM promotes community efforts to improve self-management, including exercise classes for the elderly at senior centers. Healthcare institutions must form partnerships with local programs and organizations to extend the responsible disease self-management model into the community. While promoting collaboration between institutions and local community organizations is a CCM tenet, it is also consistently endorsed by the World Health Organization (WHO) (RWJF, 2009).

Community development and local partnerships are critical to public health best practices. Community development means "the process of organizing and supporting community groups in identifying their health issues, planning and acting upon their strategies for social action, social change, and gaining increased self-reliance and decision-making power as a result of their activities" (RWJF, 2009, pp 15). The community then becomes a trusted access point for outreach programs to increase disease self-management awareness and compliance.

Community diabetes outreach programs focused on those diagnosed with diabetes, those at risk for diabetes, and those undiagnosed but with diabetes, through schools, churches, parking lots, and homes. Community partnerships bridge the gap between healthcare providers where there are issues of culture, literacy, and social class hampering access to needed health care. Studies found that these types of outreach increase attendance at free diabetes, self-management training courses in the community (Tsai et al., 2005). Community programs are uniquely situated to find those living on the margin in society and most in need of diabetes treatment and self-management education. Realizing the potential for community-based outreach programs will bridge the gap between sophisticated best practice disease management and those who need it most (Whittemore, & Dixon, 2008).

Self-management Support

The core of CCM diabetes care is disease self-management. Quality of life and self-reported health for those with diabetes depends largely on effective self-management (RWJF, 2009). This means more than having a primary care physician tell a patient what must be done, it means having the patient take personal responsibility for their own health. Diabetes self-management support includes diabetes self-management education (DSME), psychosocial and emotional support for the patients and family, strategies for living with diabetes, and a system design including a registry and proactive reminders (RWJF, 2009). The CCM promotes collaboration between patients, physicians, educators, dietitians, social workers, and pharmacists managed by an efficient clinical information system.

Despite dramatic strides in technology, many patients with diabetes are suffering debilitating complications, diminished quality of life, and increased morbidity and mortality. These results are a manifestation of a broken healthcare system without the necessary infrastructure to support the self-management needs of the chronically ill. Traditional diabetes management asks the health provider to provide a set of instructions to the patient, and the patient must comply or take an additional risk (Whittemore, & Dixon, 2008). Self-management success is determined by the ability to comply with a structured care program with the support of DSME, reminders, community support, caregiver education, and consistent primary care follow-up. The traditional model of issuing advice and leaving is replaced with the development of a multi-faceted action plan with a team of caregivers and a supportive system design.

Diabetes Self-Management Education

Since the 1930s, Diabetes self-management education (DSME) has been taught of as a significant part of the clinical management of diabetes. DSME is the way individuals with diabetes are taught to manage their disease and the American Diabetes Association (ADA) recommends annually evaluating diabetes self-management skills, knowledge, and encouraging continues education (Norris et al., 2002, para.1).

According to the American Diabetes Association (2010), a task force was put together to review the current DSME standards for appropriateness, relevance, and scientific basis. The Standards were then reviewed and revised based on the available evidence and experts' consensus. Organizations that form part of the task force were: the American Association of Diabetes Educators, the American Diabetes Association, the American Diabetic Association, the Veterans' Health Administration, the Centers for Disease Control and Prevention, the Indian Health Services, and the American Pharmaceutical Association. Members included a person with diabetes; several health services researchers and behaviorists, registered nurses, and registered dietitians; and pharmacists.

Diabetes self-management education sought to teach individuals to self-manage their diabetes through a process of promoting knowledge and skill acquisition (Tsai et al., 2005). Diabetes self-management education empowered the patient to be the most knowledgeable and active participant in his or her diabetes care by understanding the disease, its treatment, and modifying behavior during the early, reversible stages and mastering self-management behaviors. More broadly, DSME provided the tools to meet the mental, emotional, and physical demands of diabetes, given their unique circumstances (Whittemore, & Dixon, 2008).

Diabetes Self-management Education devolved from unstructured, episodic private care provider instruction to comprehensive, formalized self-management education programs delivered in a private care setting and online. The evolution was prompted by changes in insurance coverage, hospitalization procedures, and a desire to reduce variability in the quality education delivery (Tsai et al., 2005).

The American Diabetes Association (ADA) provided endorsements to recognize outstanding diabetes education programs. The National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) initiated the National Diabetes Education Program (NDEP) to promote early diagnosis and to improve self-reported health. The NDEP's promotes glycemic control, lipids, and blood pressure to mitigate the most severe complications of diabetes. Diabetes Self-management Education moved from an ancillary healthcare delivery function to an essential priority (RWJF, 2009).

One goal of DSME was to provide the tools to optimize metabolic control, prevent complications, and maximize quality of life. Studies consistently demonstrated that DSME improved self-reported health (RWJF, 2009; Tsai et al., 2005). Studies also showed significant knowledge and skill deficits in between 50% and 80% of people diagnosed with diabetes. Research demonstrated that DSME improved disease self-management and compliance as measured by disease knowledge, psychological measures, and behavioral measures (blood glucose testing, physical activity, eating behaviors), all of which positively affected compliance and long term self-reported health, and reduced diabetes-related complications. Studies found that diabetes patients without DSME were four times more likely to develop a major complication (Tsai et al., 2005).

Diabetes Prevalence

It was estimated that as of 2012, approximately 29.1 million people which is roughly 9.3% of the U S population were diabetic. Out of that number, 21 million were formally diagnosed, and 8.1 million or 27.8% are undiagnosed, (ADA, 2014; CDC, 2014). For those aged ≥ 65 years, it was estimated that 11.8 million or roughly 25.9% of them had diabetes. A total of 1.7 million Americans age 20 years or older were newly diagnosed in 2012 alone, in 2010 it was about 1.9 million which showed a slight reduction; in 2012, 86 million or 37% of Americans between the ages of 20 years and older had prediabetes. This is a slight increase from 35% in 2010, and it is currently at 51% from 50 % among those aged ≥ 65 years (ADA, 2014).

In 2010, the seventh leading cause of death in the United States was diabetes and related complications (CDC, 2011). Although the incidence of type 2 diagnoses was increasing, the death rate was falling due to improved disease management (Gregg et al., 2012). Diabetes is a group of diseases that typically starts gradually where an individual’s ability to produce insulin is compromised inhibiting their capability to sustain sufficient glycemic control (CDC, 2011).

Type 2 diabetes is associated with pregnancy, obesity, family history, physical inactivity, age, and race and ethnicity. In the United States, the prevalence of diabetes for non-Hispanic Blacks was substantially higher than non-Hispanic whites or Asian

Americans (ADA 2013). Type 2 diabetes prevalence for non-Hispanic Blacks was 13.8% compared to 15.9% for American Indians/Alaskan Natives, 12.8% for Hispanics and 9% for Asian Americans and 7.6% for non-Hispanic Whites (ADA, 2014). The prevalence of diabetes continues to rise in both the United States and globally; 95% of all cases are type 2 diabetes (CDC, 2012).

African Americans

For the purpose of this study, individuals who have self-identified as having origins in any of the Black racial groups of Africa are considered Blacks or African Americans. They include individuals who marked their race as Black, African American, Negro, Sub-Saharan African (e.g., Liberian and Guinean), or Afro-Caribbean such as Haitian and Jamaican. This population has a very protracted history in the United States. Some African American families have been in the United States for many generations; others are recent immigrants from places such as Africa, the Caribbean, or the West Indies (CDC, 2014).

Based on the 2010 U.S. Census, it was estimated that the total United States population was 308.7 million; out of which those who considered themselves as African American only are 39 million or 13.1 %. African Americans, and those individuals who are of more than one race is 44.5 million or 14.2% of the total United States population and that number is anticipated to increase to 77.4 million or 18.4% by 2060 (CDC, 2014).

African American women are at greater risk for diabetes than the general population and non-Black women. United States diabetes prevalence among African American women is 14.7% compared to 8.6% for the general population and 6.5% for non-Hispanic White women (ADA, 2014). The variance was partially attributable to a greater predisposition for diabetes for all African Americans, and certain behavioral factors such as poor dietary habits (low levels of vegetables and fruits and high level of fat), and comparatively low levels of physical activity (Zhou, Remsburg, Caufield, & Itote, 2012).

Other risk factors for African American women include lack of access to preventive care, poor stress management, inadequate routine health care and follow-up, lack of health insurance, failure to take medications, a lack of knowledge, and negative cultural attitudes regarding diabetes management (August & Sorkin, 2011; Liao et al., 2011; Zhou & Oh, 2012). Figure 2 shows diabetes statistics for American population with diabetes for 2010 and 2012, and Figure 3 shows rates of diagnosed diabetes by race or ethnicity.

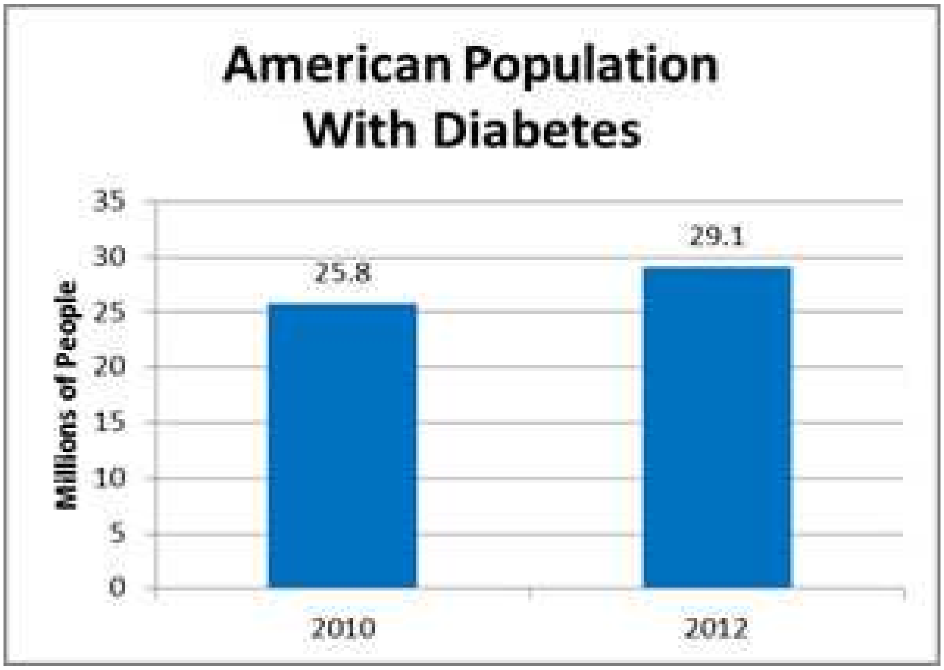


Figure 2. Rates of diagnosed diabetes (ADA, 2014).

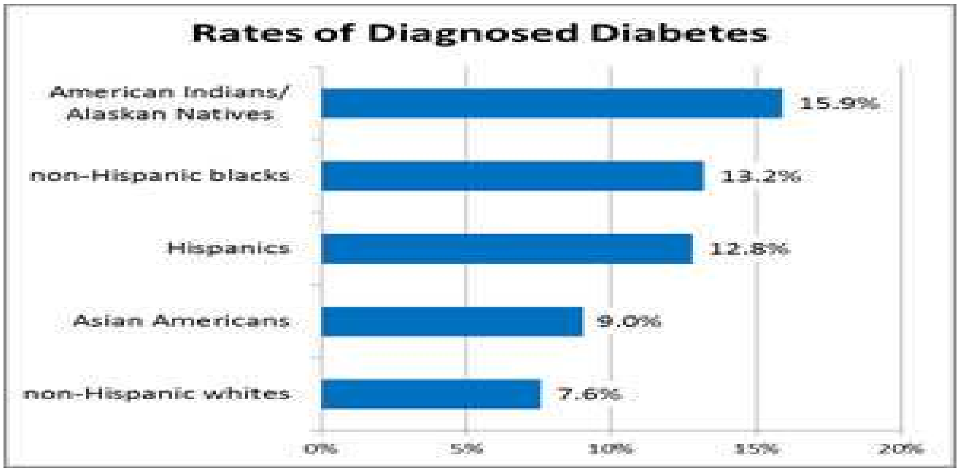


Figure 3. Rates of diagnosed diabetes by race (ADA, 2014).

Determinants of Glycemic Control

Although family history and genes play a role in the risk for poor glycemic control and diabetes-related complications, lifestyle or lack of physical inactivity, poor diet, and excess body weight significantly increase this risk. Risk factors for diabetes include age (being 45 years of age and older), low levels of HDL cholesterol, and hypertension. Diabetes and increased systolic blood pressure significantly worsen patient prognosis with respect to microvascular and macrovascular complications (Mezuk, Eaton, Albrecht, & Golden, 2008).

In addition, important psychosocial factors were found to contribute to glycemic control and long-term management of diabetes in adults. Some of these factors were fear, anxiety, and depression, which were associated with poor quality of life, as well as relevant risky behaviors such as smoking and high caloric intake, which can increase the risk of uncontrolled glucose. As noted above, a family risk of diabetes can also be a significant predictor of further complications such as CVD (Mezuk et al., 2008). This is of significance given that certain racial and ethnic minorities, particularly Hispanics, are growing rapidly in the United States, and thus the risk for diabetes is likely to increase as well. The contributing effects of appropriately self-managing glycemic control, including the impact of psychosocial variables on the individual and the influence of caregivers, should not be underestimated.

A review of the diabetes literature examined methodologies for diabetes self-management that included coping, interventions with diverse populations, peer support, goal setting, problem-solving, and coping skills. Psychosocial interventions such as cognitive behavior therapy and collaborative care for treating depression as well as family therapy made noticeable differences in self-management behaviors (Thorpe et al., 2012).Thorpe et al. (2012) suggested that there is a need for further research in the growing population of older, fragile patients with diabetes and those with comorbidities. Poor glycemic control may be more prevalent among the older population and the difficulty of patient and caregiver management of glycemic control is of greater concern, suggesting the need for further assessments. Effective approaches to increase diabetes glycemic control are needed to improve clinical outcomes and reduce the burden imposed by diabetes.

Medical approaches to diabetes self-management alone do not consistently meet patients’ family needs psychological support or adequate health information. Several studies found that one of the main barriers for patients to achieve glycemic control is the lack of knowledge to achieve adequate control (McCleary, 2011). These studies conducted with ethnic minorities identified specific barriers to self-management, which served as important factors for creating interventions that may improve health. The dietary behaviors of ethnic minorities can be challenging for many reasons because traditional food practices and religious customs or family rituals around food often influence them. Other barriers to self-management included a lack of knowledge about how to control diabetes and challenges in coordinating care with specialist providers to address such topics as nutrition, foot, and vision care, and family involvement and support. Previous studies identified other sources of health disparities among minority populations (McCleary, 2011), which led to the establishment of a chronic care model for chronic disease management. Moreover, the absence of supportive governmental policy, inadequate understanding of population-based management, insufficient information systems to maintain health, and lack of social support were also associated with patterns of treatment non-adherence (Osborn et al., 2011).

According to Wagner et al. (2008), patient preferences and attention to psychosocial issues such as distress about illness, environments, depression, and anxiety were identified and measured within the area of diabetes self-management. Male patients relied on their caregiver spouses or partners for assistance with medical needs as well as trusted sources of information, more so than females (Mosca et al., 2012).

Female patients were more likely to use the internet and less likely to rely on nurses than male patients with vasculities, signifying that medical providers may want to involve caregivers who are spouses or partners in medical care (Mosca et al., 2011). The previous statements are both important and relevant management components that contributed to disease-related outcomes, but, as noted before, the influence caregivers have on patient outcomes has not been extensively studied. In short, standard behavioral interventions for diabetes often fail to address the complex psychosocial factors stemming from health disparities that complicate care (Thorpe et al., 2012).

Encouraging preventive approaches that facilitated nutrition helps glycemic control and prevents complications, particularly in the early stages of the disease process. Diabetes self-management interventions that incorporate patient empowerment were effective in addressing the psychosocial aspects of living with diabetes (Mosca et al., 2011). Community-based peer-led diabetes self-management support programs to improve diabetes self-management have positively affected underserved populations. These self-management support programs include encouraging the participation of family members as a form of support to diabetes self-management. Interventions that involve the patient and family caregivers in the process of self-management and support were cited in the diabetes standards of care. Basic self-care activities taught in self-management curricula described the disease process and treatment options at an individual level. Non-professionals, such as family members or unpaid caregivers, contributed to diabetes self-management support (Haas et al., 2012).

To improve care for those who have diabetes, the literature suggested that (a) improving glycemic control, (b) increasing comprehensive diabetes management, (c) coordinating transitional care to increase patient adherence to medical guidelines and address the current fragmented health care system, and (d) empowering patient-care teams by educating patients and caregivers were considered essential components of diabetes management. However, one barrier to establishing these strategies is limited knowledge, particularly in how caregivers relate to glycemic control among hospitalized patients with diabetes.

Chronic Disease Management

While there is no known cure for diabetes, death rates have declined over time due to improved disease management practices. Diabetes management includes self-management of medication treatments, adherence to healthy eating habits, and regular physical activity regimen as part of a lifestyle routine to improve glycemic control (Montori & Fernandez-Balsells, 2009; Sinclair, Armes, Randhawa, & Bayer, 2010). Effective control of chronic poor glycemic levels for individuals with type 2 diabetes included insulin medication management, self-management education and support (Ross, Tildesley & Ashkenas, 2011). The consequence of the absence of this care and support is more frequent admissions to medical centers, which resulted in increased out of pocket costs for the disease.

Cultural barriers exist for certain ethnic minorities regarding disease self-management. Barriers include: lack of education, hopelessness that the type 2 diabetes is permanent and cannot be cured, trepidation regarding the health care system; limited access to the health care system, limited financial resources, and lack of family support. Since all of these limitations and barriers exist for ethnic minorities, treatments based on medical centers or hospitals would seem unlikely to meet the needs of this population with regards to getting the proper support for the patients' management of the disease (Garzmararian, Ziemer, & Barnes, 2009; Reichsman et al., 2009).

Research indicated that glycemic control protocols might be more effective if they are tailored specifically to each individual according to ethnic background, gender, and age. Psychosocial needs included perceived problems with self-management, obtaining social support, comprehending knowledge of the disease, accepting the diagnosis and coming to terms with having diabetes as well as glycemic control (Misra & Lager, 2009). Other studies suggested that for African American, the most significant difficulties facing this community are exercise levels and healthy diets (Leger, 2010). Other ethnic differences were suggested by research, including eating habits, attitudes towards healthy behaviors, and desire to exercise. Hispanic and African American men were more likely to exercise than ethnic women (Gavin, Fox, & Grandy, 2011).

African American women were more likely to adopt healthy eating plans at their health care providers urging as part of a self-management plan (Mochari-Greenberger, Terry, & Mosca, 2011). African American women were also more likely to respond to education about disease self-management than African American males (Jenkins et al., 2010). African Americans were less likely to have access to quality healthcare (Mann, Ponieman, Leventhal, & Halm, 2009; Wang et al., 2009).

African Americans and Hispanics were substantially more likely to seek treatment at a hospital or medical center when their diabetes became acute, as opposed to preventive care or early intervention. As a result, hospitals and medical centers served as a critical focal point for attending to their medical needs particularly for chronic or potentially fatal diseases such as diabetes. Hospitals and medical centers role was to initiate an individualized disease management protocol and hand the patient off to a general practitioner, family member or community resource. Patients with diabetes who are hospitalized or under the supervision of a medical center offer the best opportunity for both treatments as well as a study. In America, patients go to hospitals or medical centers more than 233 times a year, with an incidence of diabetes related problems of approximately 58% (Wang et al., 2009).

Due to these facts, the optimal setting in which to teach both patients and caregivers in a culturally sensitive manner was in a community hospital or medical center. Education with regard to diabetes management and preventive care as well as assistance with follow-ups and referrals (all of which are critical components of glycemic control was administered by the health care team using a culturally sensitive approach to both patients and their caregivers while they were patients in either a medical center or hospital. In this manner, caregivers became an important part of the caregiving team while getting support from the professionals at the hospital or medical center. There has only been a handful of studies investigating the association between glycemic control, caregivers, and self-reported health, particularly for adult populations. Given the diabetes epidemic, there was a need for multiple professional and academic disciplines to work together to improve disease management protocols to improve health outcomes (Codispoti, Douglas, McCallister, & Zuniga, 2004).

Caregivers and Diabetes Self-Management

The research caregiver interventions are in its infancy, and much work remains to be done to identify how caregivers' management education can lead to the best outcomes for people with diabetes. Paid and unpaid caregivers were contributors to optimal self-care and positive mortality and morbidity outcomes for those with type 2 diabetes (Dunbar et al., 2008).

A caregiver is defined as someone who provides either paid or unpaid help to another person in need. The individual receiving care was typically either a child or an adult with medical needs and the person providing the care was frequently a family member. The American Association of Retired People (AARP) and the National Alliance for Caregiving (NAC) defined a caregiver as either an unpaid individual or a paid professional (e.g., a nurse, home attendant or aide) who supports someone else with medical care (AARP, 2009). Additional research on caregivers defined unpaid caregivers more specifically as individuals who are not a component of the official paid caregiving labor force (i.e., typically family members such as spouses and children within the family). In many cases, the person being cared for was suffering from a chronic illness or needs to take multiple medications.

Many times, the unpaid caregiver was a family member who was able to help patients effectively manage their illness if they were provided sufficient instruction, had adequate support systems and were regularly supplied with updated information (Levine et al., 2010). For example, individuals inflicted with a chronic obstructive pulmonary disease (COPD), spouses, and other unpaid caregivers helped patients stick to their medication guidelines (Trivedi, Bryson, Udris, & Au, 2012).

In large suburban areas, relatives played a key role in helping family members with chronic illnesses stick to treatment regimens. Given these findings, it only made sense that caregivers should be incorporated into assisting in patient's glycemic control process (Trivedi, Bryson, Udris, & Au, 2012).

The primary types of support that caregivers offered to patients include: (a) instrumental services (cooking, cleaning, and administrative assistance) and (b) daily living or occupational activities (mobility or moving around, eating and drinking, personal hygiene). For individuals suffering from chronic conditions, researchers have demonstrated that caregiver assistance led to an improved quality of life (House, Umberson, & Landis, 1988). Moreover, studies on heart attack patients revealed that death is connected to an absence of support, when taking other socio-demographic variables, risk factors and diseases into account (Berkman, Leo-Summers, & Horwotz, 1992). In addition to generally supplying assistance and helping with a patient's well-being, caregivers were an important ingredient of a dynamic causal process that is comprised of psychobiological health interactions (Berkman, Glass, Brissette, & Seeman, 2000).

Studies have shown that relatives of individuals with chronic illnesses are a key component of their long-term care. As the health care systems in America have become increasingly more complicated and challenging, many of the duties associated with managing chronic illnesses have fallen on relatives (Aggarwal, et al., 2009; Cassie & Sanders, 2008; Hwang et al., 2011; Talley & Crews, 2007). There were specific examples of the potential for the functions that relatives fill in supporting observance to treatment programs outside of America. For example, in Thailand the existence of a caregiver was associated with improved adherence to treatment regimens. In this instance, strictly following the precise processes and procedures was critical for successfully growing antiretroviral therapy (ART) plans. This research demonstrated that when relatives are supplied with sufficient details and particulars, they were relied upon to effectively partner with patients in the observance of long-term treatment programs (Knodel et al., 2010).

Other studies have presented correlations between family interventions and managing chronic illness. Dunbar et al. (2008) indicated heart failure patients with family members that encouraged patients', showed empathy, and promoted the patients' self-care regimen, showed significantly lower recurrence of heart failure (e.g., adhering to a special diet, controlling fluid intake, daily weighing, or exercise). These findings suggested that family caregiving involvement in chronic care improved health outcomes. The Dunbar et al. (2008) study emphasized positive family relations, such as high family solidarity and low conflict, to improve glycemic control and overall health.

A large-scale, longitudinal study by Blazer (1982) found a significant association between family support and health outcomes (involving 6,229 people and a 9-years follow-up period from Alameda County, California). Marriage and contact with friends were the highest predictors of decreased mortality (Blazer, 1982). Caregivers may offered a critical opportunity to assist patients in managing diabetes self-care activities, and evidence suggested that they also act as important health care partners by becoming involved in diabetes care. For example, Rolley et al. (2010) found an association between the presences of caregivers decreased lengths of hospital stays, and improved self-management behavior. A common theme that surfaced was the caregiver's need for support and information. These findings highlight the necessity of including caregivers in care planning and decision-making while simultaneously providing support and resources.

The contributions and experiences of family caregivers were considered in gathering information to shape policies and practice, training health care professionals, developing programs, and reforming financing. Haas et al. (2012) posited that women with better glycemic control were influenced by family members who took on new roles as care providers. Consequently, nutrition education was directed toward assessing existing family environments by helping women organize and supplement diabetes self-management tasks for hospitalized patients. To a certain extent, the support that family caregivers was considered an important link to health and behavior in people with chronic diseases. For example, patients with CVD described caregiving as family members providing assistance with daily living tasks (i.e., eating, drinking, bathing, or providing night care).

In another study, caregivers strove to reduce disability and hospital re-admission in people with heart failure (Hwang et al., 2011). In Mochari-Greenberger, Terry, & Mosca, (2011), lipid data among hospitalized patients with CHD showed that having a caregiver was associated with adherence to LDL cholesterol goals and statin medication use. Moreover, gender-related variations were also found: men who had unpaid caregivers had adequate LDL cholesterol goals, but the benefit was less likely for women.

Research on Caregiver Status and Disease Management

Research on the relationship between caregiving and disease management interventions was in its infancy. Unpaid caregivers were found to be important contributors to health outcomes, mortality and morbidity outcomes (Dunbar et al., 2008, Mosca et al., 2012). Patient outcomes and adherence to medication treatment were shown to improve with adequate education and social support. This suggested that family members and those providing care at home could play a greater role in clinical care focused on improving patient self-care. Support from family and health care professionals was believed to correlate positively with adherence behaviors by providing cues to action and direct assistance or tools such as reminders, reinforcement, and knowledge for self-management behaviors.

The Family Cardiac Caregiver Investigation to Evaluate Outcomes (FIT-O) study (Mosca et al., 2012) was the first large-scale study regarding caregiver status and health outcomes. The purpose of the FIT-O study was to evaluate the patterns and characteristics of caregivers among patients who were hospitalized for a CVD assessment or intervention from November 2009 to June 2010. The FIT-O study also sought to determine the association between cardiac caregivers and clinical outcomes.

The FIT-O study consisted of 4,500 consecutive patients who were admitted to a hospital cardiovascular service line (59% White, 62% males) (Mosca et al., 2012). These patients completed a standardized interviewer-assisted questionnaire in English or Spanish regarding assistance with activities of daily living or instrumental tasks in the past year and their plans for post hospitalization. The Caregiver Status Form used in the

FIT-O study was used in the instant study. In the FIT-O study, the caregiver was defined as either paid or professional (i.e., nurse or home aide) or unpaid (i.e., family member or friend). The FIT-O study showed that having a paid caregiver was more prevalent among racial or ethnic minority than White patients. Patients who had unpaid caregivers in the year prior to hospitalization reported that grocery shopping, meal preparation, transportation, arranging doctor visits, medication adherence, and medical needs were the main tasks for which caregivers assisted patients.

Following the baseline study on the patterns and characteristics of caregivers, a prospective study was conducted with a cohort of 3,188 patients who had 1-year follow-up data by June 2011 to evaluate clinical outcomes (rehospitalization and mortality) (Mosca et al., 2012). A 1-year follow-up survey was systematically mailed and pursued by telephone after the index hospitalization occurred. Each patient's follow-up survey corresponded with the patient's baseline survey interview data regarding rehospitalization in the previous year (Mosca et al., 2012).

The FIT-O study reported that having a caregiver of any kind was associated with rehospitalization or death at 1 year. Patients with paid caregivers were twice as likely to be rehospitalized as patients with unpaid caregivers, even after accounting for age, racial or ethnic minority status, a lack of health insurance, medical history of diabetes mellitus or hypertension, and comorbidity. In summary, the risk of rehospitalization or death was significantly greater among cardiac patients with caregivers and was not fully explained by the presence of traditional comorbidities (Mosca et al., 2012).

FIT-O was a well-designed, large-scale study of caregiver status and health outcomes but was based on rehospitalizations only. The association between paid caregiver and re-hospitalization was the strongest correlation, even after accounting for comorbidity. The presence of a paid caregiver was indicative of a more severe illness that is not comorbidity, but rather a more severe CVD or later stage diabetes. The challenge for caregiver research was to isolate the variance in health to the caregiver alone. This study was an effort to add to the base of knowledge on the effect caregivers have on patient health.

Family Context and Disease Self-management

The quality and quantity of family involvement in disease management, significantly affected health (Dunbar et al., 2008). The relationships among *family context*, *clinical characteristics*, and *individual characteristics* drove *self-management behaviors* and played a significant role in both self-reported health status and caregiver burden. *Self-management behaviors* involved in self-care decisions and actions were influenced by *individual demographic characteristics*; patient's *clinical characteristics* (illness severity, etc.); *behavioral characteristics (*motivation, self-efficacy, mood, resilience, etc.); and the *requisite knowledge and skills. D*ietary self-care was focused on dietary sodium in diabetes management, identifying foods high in sodium content, and an understanding of potential alternatives. Successful self-management and self-care o*utcomes* referred to a combination of adherence and an improvement in both physical and psychological health. Figure 4 depicts a framework for understanding the relationship between and among these factors.

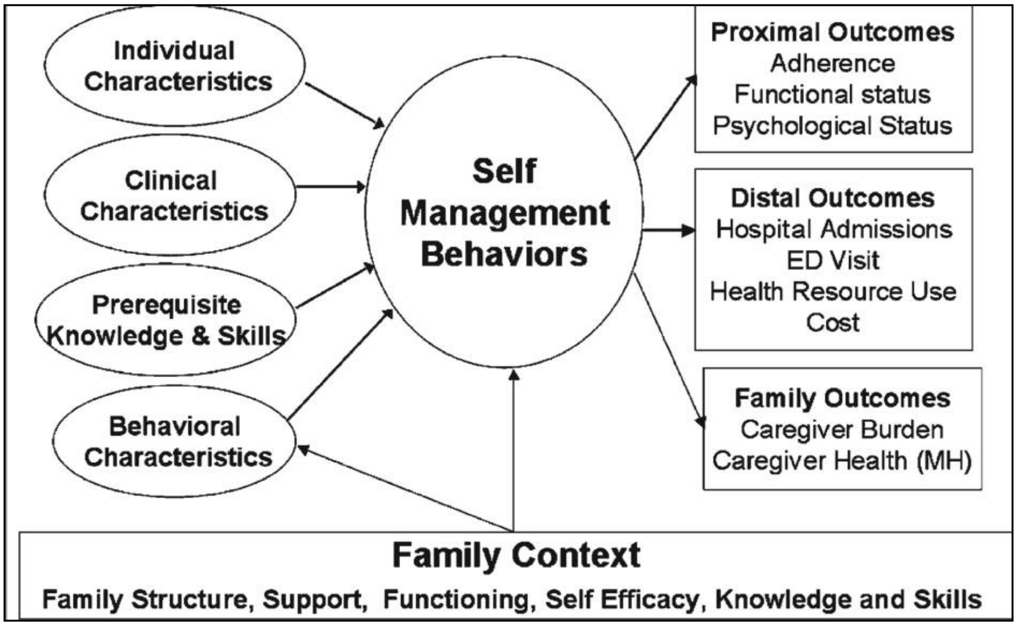


Figure 4. Self-management behaviors (Dunbar et al., 2008, p. 9).

Positive self-management behaviors include healthy eating, medication taking compliance, and physical activity. *Family context* includes function dimensions of adaptability, problem solving, communication, and roles. While other models vary the order and relationships among factors, poor family functioning is associated with worse self-reported health for the chronically ill. Research indicates that negative family characteristics, such as poor relationship satisfaction, high hostility and conflict, and a tendency to be critical are associated with poor chronic disease process and negative self-reported health (Dunbar et al., 2008). The ones considered most powerful and consistent across chronic illnesses and age include low congruence in disease beliefs and expectations.

Social isolation, living alone, and the lack of a caregiver have been correlated higher mortality and morbidity for chronic disease patients. Marital status is often used by researchers as a proxy for social support and caregiver status. Unmarried heart failure patients have higher mortality rates even after accounting for covariates, such as heart failure and depression (Friedman et al. 2006). Individuals diagnosed with type 2 diabetes and unmarried, are more frequently depressed, and experienced a lower quality of life and more rehospitalizations (Dunbar et al., 2008). Social support for enhanced self-care seems to be a significant factor in improving health outcomes.

Wu et. al. (2012) studied 136 heart failure patients over a three-month period. The study found that married patients' prescription administration compliance was 90%, while those without a spouse was only 80%. The administration of medication on time was also an issue. However, married patients took nearly 70% of their medication on time and compared to 49% for those without a spouse, a significant difference. In addition, Wu et al. (2012) found that single patients were more likely to be medication non-compliant with medication adherence and twice as likely to have a detrimental episode as a result ($p = .017$). While neither study used a randomized design, both studies reported consistent results at the $p \leq 0.05$ significance level.

Psycho-Educational Interventions

Psycho-educational interventions include behavioral interventions and educational components concerning disease management. The most commonly used methods in diabetes self-management training include patients, family, and caregiver education to recognize symptoms and incorporate cognitive behavioral skills for coping. Follow-up phone calls and telephone interventions by health educators have also been successful in diabetes self-management, modestly improving diabetes control (Wu, Forbes, Griffiths, Milligan, & While, 2010). Additional support and anticipatory guidance for care recipients or caregivers may also be helpful during care transitions.

A study conducted on cancer patients and their caregivers suggests that psycho-educational interventions to help caregivers and patients to manage their disease and improves patient quality of life (Norris, Nichols, & Caspersen, 2002). More specifically, the study found that information about symptom management, physical changes, and the emotional and psychosocial needs of patients and caregivers improved self-reported health measurably. Similarly, an intervention study of patients with chronic obstructive pulmonary disease (COPD) and their caregivers included sessions that promoted physical activity, relaxation, cognitive restructuring, communication skills, and problem-solving (Blumenthal et al., 2009). This study intended to associate caregiving training with all-cause mortality and COPD-related hospitalizations, physician visits, and quality of life. Encouragement of physical activity and the inclusion of caregivers as patient coaches to enhance the effectiveness of the intervention were found to be effective.

Patient outcomes and adherence to medication treatment have also been shown to improve with adequate education and social support. This suggests that family members and those providing care at home could play a greater role in clinical care focused on improving patient self-care. Support from family and health care professionals is believed to correlate positively with adherence behaviors by providing cues to action and direct assistance or tools such as reminders, reinforcement, and knowledge for self-management behaviors.

Other studies have examined the influences of family behaviors among adults with chronic diseases such as arthritis, CVD, diabetes, and end-stage renal disease (Reichsman, Werner, Cella, Bobiak, & Stange, 2009). The importance placed on family involvement in diabetes education, and management has also been previously documented (Sinclair, Armes, Randhawa, & Bayer, 2010). Family involvement was significantly related to the emphasis on family during the education of certified diabetes educators (CDEs). Therefore, increasing formal education on the importance of family involvement in self-management behaviors could positively affect individual diabetes self-management behaviors, including HbA1C monitoring for glycemic control.

Summary

Families seem to be the foundation of long-term care, which policymakers conventionally refer to as “informal” or unpaid caregivers. The relentless drive to reduce healthcare costs, and the increasing burden placed on the healthcare system from diabetes has shifted much of the diabetes medical management to families. Enhancing family involvement, training, and support may contribute to reducing unnecessary hospitalizations and improving patient outcomes.

The burden of caregiving has also been documented in studies on patients with Alzheimer disease, cancer, and mental health. However, there remains a gap in the knowledge and assessment of caregivers of hospitalized patients with diabetes, according to gender and racial or ethnic status differences, and the association between caregivers and patient outcomes.

Despite these studies, however, future research continues to be needed to include more racial or ethnic minorities to further understand caregiver influence on glycemic control and to tailor educational programs to people with diabetes. More research is also needed to identify gender differences among those who are at higher risk for poorer outcomes, such as patients hospitalized with diabetes. Caregivers can gain information for patients who are at greater risk for diabetes-related complications which will likely benefit the most from these interventions.

Chapter 3 details the methodology for this study, including the research design, setting and sample size, participants, instrumentation, procedure, data analysis plan, limitations, delimitations, and ethical considerations.

Chapter 3: Research Design and Methodology

The purpose of this study was to examine the relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes. The study used a quantitative research design; a convenience sample of 186 AAW diagnosed with type 2 diabetes, no longer working due to illness or retirement and had either a paid or unpaid caregiver. Self-reported health status was based on answers to certain survey question 8 (Appendix B) that relate to the individual's report of their symptoms, behaviors, beliefs, attitudes, or other psychological variables (CDC, 2012a). Health outcome data was collected using the Diabetes Care Profile developed and validated by (Fitzgerald et al., 1996).

Research Design and Rationale

The study used a quantitative research design to examine the relationship between caregiver status and self-reported health status for AAW diagnosed with type 2 diabetes after controlling for covariates, age, education and marital status. A quantitative methodology design was an appropriate choice because the dependent and independent variables were measured and, in this case, a validated instrument was available for self-reported health status (dependent variable) (Leedy & Ormrod, 2012). In a quantitative study, hypotheses were tested and rejected or accepted based on discrete data. According to Leedy and Ormrod (2012), the use of a quantitative methodology was appropriate when: (a) the independent and dependent variable were clearly stated and measurable, (b) the research problem was clearly understood, and (c) there was a need for high levels of precision and accuracy from controlled observations. No attempt was made to affect the participant's behavior, making the proposed research non-experimental in nature.

The research design was correlational. In a correlational research design, relationships between two or more variables are investigated without manipulating the variables (Jackson, 2011). With correlational research designs, causality cannot be determined.

Alpha Level

The alpha level is the point at which the null hypothesis is rejected assuming that the null hypothesis is true. In social sciences, the alpha level is $p < .05$ (Brace, Kemp, & Snelgar, 2009).

Power Analysis

A power analysis was conducted with G*Power 3.1 (Faul, Erfelder, Lang, & Buchner, 2007). For an odds ratio of 2.0 and a power level of .95, a sample size of 180 is required. See Figure 5.

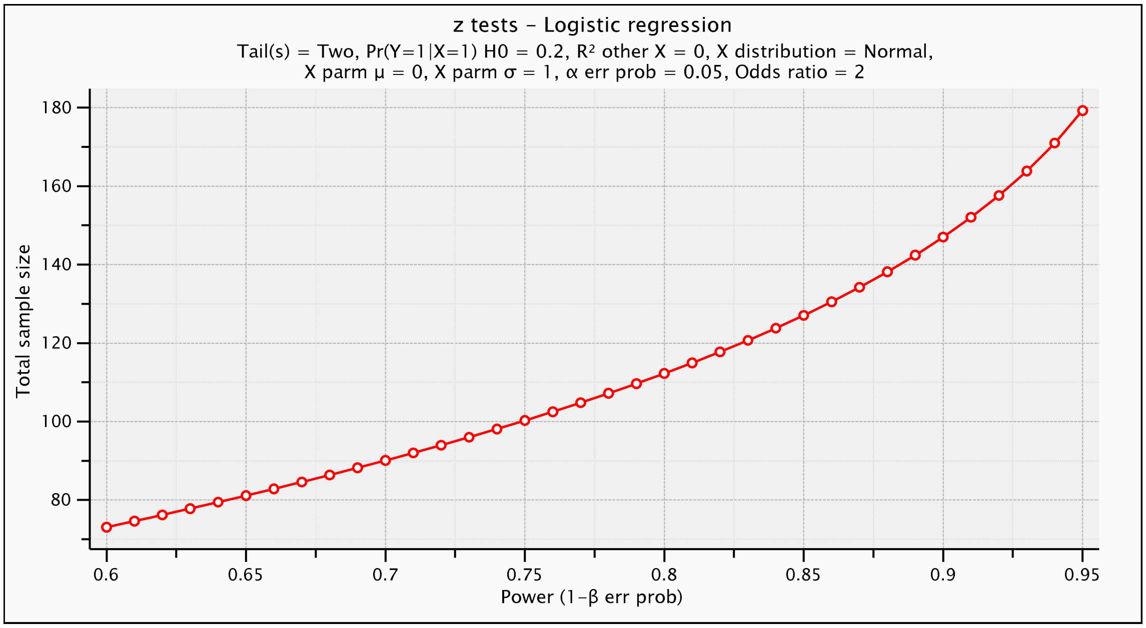


Figure 5. Power analysis.

Methodology

Participants and Sampling Procedures

A sample of 186 AAW diagnosed with type 2 diabetes, no longer working due to illness or retirement, participants were adults 18 years or older, and have either a paid caregiver or unpaid caregiver. Participants were recruited using Survey Monkey, a commercial survey application and service. The selection method for participants was a non-random convenience sample solicited through commercial survey applications. The research design is correlational. In a correlational research design, relationships between two or more variables are investigated without manipulating the variables (Jackson, 2011). With correlational research designs, causality cannot be determined.

1. Each observation was independent of all the others, and
2. All expected counts were expected to be 10 or greater (Yates, Moore, & McCabe, 1999).

Procedures

A consent form was required before a participant viewed and completed the diabetes care profile (DCP) and caregiver surveys. It took 30 minutes to complete the surveys. The consent form contains both the researcher's contact information and the IRB's, and participants were asked to please print a copy of the consent form for their record. Survey Monkey service recruited participants. Survey Monkey has a pool of 30 million members who complete more than 2 million online survey responses every day. Potential participants were asked to complete three documents: (a) Consent form, (b) the diabetes care profile survey, and (c) caregiver status form using the survey monkey online portal. In 90 days, data generated within Survey monkey's application were downloaded to researcher's computer for analysis.

Instrumentation

The DCP is a 234 item self-administered questionnaire designed to measure social and psychological factors related to diabetes treatment and health status. The DCP also contains questions concerning demographic information and self-care practices. A subset of 18 questions was used for this study. Study questions included multiple choice and 5-point Likert scale questions using *strongly disagree, somewhat agree, neutral, somewhat disagree and strongly agree*, corresponding form one through five, respectively. Fitzgerald et al. (1996) conducted two studies to validate the DCP.

In the first study, the DCP was administered to individuals with diabetes being cared for in a community setting (n = 440), and 65% of the participants were African American women. In the second study, the DCP and several previously validated scales were administered to individuals with diabetes receiving care at a university medical center (n = 352), and 54% of study participants were African American women. Cronbach's alphas of individual DCP scales ranged from .60 to .95 (Study 1) and from .66 to .94 (Study 2) (Fitzgerald et al., 1996). Fitzgerald et al. (1996) reported statistically significant construct, content, and concurrent validity with previously validated scales of all 14 subscales.

The study used DCP Question 8 as the dependent variable. The language in Question 8 was also used by the CDC to measure self-reported health status for the Behavioral Risk Factor Surveillance System (BRFSS) conducted annually (CDC, 2012a). The 2010 BRFSS was completed by 400,000 participants, and the results relied on responses to Question 8. There were no separate validity and reliability studies for the language in Questions 8. Based on its use in the DCP and by the CDC, Question 8 was assumed to be a fair representation of self-reported health status.

Data Analysis Plan

Research Questions and Hypotheses

Is there a relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes controlling for age, education, and marital status?

$H_{0:}$ There is no relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes controlling for age, education, and marital status.

H_a: There is a relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes controlling for age, education, and marital status.

Statistical Analysis

The research question and related hypothesis was investigated with binomial logistic regression. The dependent variable was self-reported health status among African American women diagnosed with type 2 diabetes. The control variables were age, education, and marital status. The variables of interest for the study are presented in Table 23.

Table 23.

Variables of Interest

Variable Name	Scale of Measurement	Variable Type	Categories
Self-report Health Status	Dichotomous	Dependent Variable	2(Good to excellent, Poor to fair)
Caregiver Status	Nominal	Independent Variable	2(Paid, Unpaid)
Age	Interval	Control Variable	N/A
Education	Ordinal	Control Variable	N/A
Marital Status	Nominal	Control Variable	2(Married, Unmarried)

Operationalization of Variables

Independent variable. Primary caregiver status was the study independent variable and was collected using the Caregiver Status Form (Appendix C). (Mosca et al., 2012). Primary caregiver status was dichotomous, derivative variable computed by summing the tasks for daily living in which participants receive assistance from caregivers. Participants were categorized as either having primary caregivers who were paid or unpaid caregivers based on the majority of responses provided on the last item in Appendix C.

Dependent variable. Self-reported health status was the study dependent variable (Appendix B, Question 8). Self-reported health status was a good predictor of future disability, hospitalization, and mortality (Jamoom, Horner-Johnson, Suzuki, Andresen, & Campbell, 2008). Self-reported health status was based on answers to certain survey questions (Appendix B) that relate to the individual's report of their symptoms, behaviors, beliefs, attitudes, or other psychological variables (CDC, 2012a). Participants were categorized into two groups: those who reported that their health was excellent, very good, or good and those who reported that their health was fair or poor (CDC, 2012a).

Covariates or Control Variables. Age, marital status, and education were found to increase the risk and severity of type 2 diabetes (Lysy, 2013) and were used as covariates in the proposed study. Age was an interval variable, education was an ordinal variable, and marital status, was dichotomized nominal variable with two categories (*married or unmarried).*

The Caregiver Status Form was used to code caregiver status for the Family Cardiac Caregiver Investigation to Evaluate Outcomes (FIT-O) study (Mosca et al., 2012). The purpose of the FIT-O study was to evaluate the patterns and characteristics of caregivers among patients who were hospitalized for a CVD. The FIT-O study also sought to determine the association between caregiver status and clinical outcomes. Total

4,500 consecutive patients admitted to Columbia Presbyterian Hospital completed the caregiver status form and the results were combined with a hospital, doctor, and lab data to analyze the association between caregiver status and health outcomes.

Validity and Reliability

The results of the quantitative hypothesis test were compared to participant responses to other related questions in the DCP. Study Reliability referred to the degree to which study procedures and instruments were repeated by another researcher with the same results (Leedy & Ormrod, 2012). Reliability was enhanced by the use of the DCP, a validated instrument. The research design, instruments, procedures, and data analysis plan were appropriate to address the research question.

Ethical Considerations

Participants were volunteers and received no remuneration or benefit from participating in this research project. Every consideration was taken to minimize any potential adverse effect arising from this study. Participants were asked to acknowledge the consent form before viewing and completing the surveys. Potential participants were notified that they were free to withdraw from the study at any time. The following was made available to participants: Procedures for selecting the sample, confidentiality assurances and procedures, acknowledgment of no remuneration, contact information for the researcher, and the IRB.

All Data and actual questionnaires remained confidential, and only the researcher has access to those records. Data collected by Survey Monkey is owned by the researcher. Survey Monkey treats researchers' surveys as private. Survey Monkey does not sell or share survey responses with third party advertisers or marketers, except in a limited set of circumstances where they are compelled by a subpoena or have gotten permission from researcher to use. Survey Monkey keeps data secured and stored on servers located in the United States.

Identifying information never appeared in the DCP and caregiver status form. After study completion, all Data generated on a computer were moved to a detachable USB external storage drive and deleted from the computer, eliminating physical access to the data from a network intrusion. The researcher stored copies of all information related to this project for at least five years. After five years, data will be destroyed**.**

Summary

The purpose of this study was to examine the relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes. The study used a quantitative research design to test study hypotheses. The study used the caregiver status survey and the diabetes care profile instrument to collect data for analysis. Chapter 4 reported the study's findings using the research design and methodology detailed in Chapter 3.

Chapter 4: Results

Introduction

The purpose of this study was to examine the relationship between caregiver status and self-reported health status and among African American women (AAW) diagnosed with type 2 diabetes, after accounting for age, education and marital status. The study was expected to make an original contribution to Public Health by identifying whether caregiver status impacts self-reported health status for AAW with type 2 diabetes. Public health leaders and policy makers might be empowered to make informed decisions and develop policies that target educational intervention to caregivers to improve self-reported health status, and reduce health care costs.

Research Question and Hypotheses

One research question, one null, and one related alternative hypothesis were formulated for investigation. They were as follows:

Is there a relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status?

H_o: There is no relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status.

H_{1a}: There is a relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status.

Chapter four was organized by the introduction to the study, data collection procedures, discussion of the survey results, research question and hypothesis testing followed by a summary. The following provides a discussion of the data collection procedures.

Data Collection

Data were collected from December 03, 2014 to January 4, 2015 through Survey Monkey®, a web-based data collection tool. The inclusion criteria for the sample were that participants were African American females, 18 years or older, diagnosed with type 2 diabetes, and no longer working due to illness or retirement.The selection method for participants consisted of a non-random convenience sample. A total of 254 participants started the survey. Of that number, 46 were eliminated for not meeting the study inclusion criteria leaving a sample size of 208. The surveys included; a) a consent form, b) 18 items from the diabetes care profile (DCP) survey, c) caregiver status form (CSF) using the Survey Monkey® online portal. The DCP is a 234 item self-administered questionnaire designed to measure social and psychological factors related to diabetes treatment and health status. Data were analyzed with SPSS for Windows.

Survey Results

Diabetes Care Profile

Respondents ranged from ages 19-99 (M = 56.20, SD = 19.72). Regarding marital status, 30.3% (n = 63) were never married and 31.3% (n = 65) were married. Marital status is presented in Table 1.

Table 1

What is Your Marital Status?

Marital Status	*n*	*%*
Never Married	63	30.3
Married	65	31.3
Separated / Divorced	26	12.5
Widowed	35	16.8
Living with a partner	19	9.1
Total	208	100.0

Approximately 15% (*n* = 32) of AAW lived alone and 85% (*n* = 176) lived with one or more people. See Table 2.

Table 2

How Many People Live With You?

Number of People	*n*	*%*	*Cumulative %*
I live alone	32	15.4	15.4
1 person	30	14.4	29.8
2 person	48	23.1	52.9
3 person	48	23.1	76.0
4 person	28	13.5	89.4
5 or more	22	10.6	100.0
Total	208	100.0	

Regarding educational attainment, 11.5% (*n* = 24) had an eighth grade or less education; 18.3% (*n* = 38) had some high school; and 22.6% (*n* = 47) were high school graduates or had their GEDs. Educational attainment is presented in Table 3.

Table 3

How Much Schooling Have You Had? (Years of formal schooling completed)

Educational Attainment	*n*	%	*Cumulative %*
8th grade or less	24	11.5	11.5
Some high school	38	18.3	29.8
High school graduate or GED	47	22.6	52.4
Some college or technical school	54	26.0	78.4
College graduate (bachelor’s degree)	28	13.5	91.8
Graduate Degree	17	8.2	100.0
Total	208	100.0	

More than half (56.7%, *n* = 118) of the participants were disabled, not able to work and 43.3% (*n* = 90) were retired. A survey question asked participants if they tested their blood sugar levels. Most respondents (79.3%, *n* = 165) tested their blood sugar levels, 9.6% (*n* = 20) did not; and 11.1% (*n* = 23) did not answer the question. If they answered “yes” to this question, they were instructed to proceed to the next series of three questions, which asked more details about the frequency of testing blood sugar levels and record keeping. Most AAW 55.8% (*n* = 116) tested their blood sugar levels seven days a week as indicated in Table 4.

Table 4

How Many Days a Week Do You Test Your Sugar Level? (Days/week)

Days/Week	*n*	%
Not Answered	41	19.7
1	8	3.8
2	10	4.8
3	10	4.8
4	11	5.3
5	5	2.4
6	6	2.9
7	116	55.8
once a month	1	0.5
Total	208	100.0

On the days that AAW test their blood sugar levels, 36.5% (*n* = 76) test their levels three times a day; whereas 9.6% (*n* = 20) test their blood sugars four times a day. See Table 5.

Table 5

On Days That You Test, How Many Times Do You Test Your Blood Sugar Level? (Time/day)

Times/Day	*n*	%
Not Answered	43	20.7
1	25	12.0
2	43	20.7
3	76	36.5
3 to 4	1	.5
4	20	9.6
Total	208	100.0

Women were asked about their record keeping relative to their blood sugar test results. Approximately two-thirds (66.8%, *n* = 139) of respondents kept records of their blood sugar test results, whereas 11.5% (*n* = 24) did not, and 21.2% (*n* = 44) did not answer the question.

Concerning self-reported health status, 81.6% (*n* = 169) rated their health status from good to excellent; whereas 18.3% (*n* = 38) rated their health status from poor to fair. Self-reported health status is presented in Table 6.

Table 6

In General, Would You Say Your Health is?

	Health Status	*n*	%	*Valid %*	*Cumulative %*
	Excellent	7	3.4	3.4	3.4
	Very Good	62	29.8	30.0	33.3
	Good	100	48.1	48.3	81.6
	Fair	34	16.3	16.4	98.1
	Poor	4	1.9	1.9	100.0
	Total	207	99.5	100.0	
Not	Answered	1	.5		
Total		208	100.0		

AAW were asked a series of six questions about wanting help and support from family or friends in various activities of daily living. They responded on a Likert scale from strongly agree (1) to does not apply (6). Generally, AAW agreed that they wanted help in the areas assessed as reflected in the mean scores. See Table 7.

Table 7

I Want a Lot of Help and Support From My Family or Friends In

Area of Support	*N*	*Minimum*	*Maximum*	*M*	*SD*
Following my meal plan.	208	1.00	6.00	4.11	1.44
Taking my medicine.	207	1.00	6.00	4.13	1.37
Taking care of my feet.	203	1.00	6.00	4.12	1.40
Getting enough physical activity.	206	1.00	6.00	4.09	1.35
Testing my sugar.	205	1.00	6.00	4.15	1.35
Handling my feelings about diabetes.	206	1.00	6.00	4.09	1.42

AAW were then asked a series of six questions about actually receiving help and support from family or friends in the same activities of daily living more than 50% of the time. Generally, AAW agreed that they received help in the areas assessed as reflected in the mean scores. See Table 8.

Table 8

More Than 50% of the Time, My Family and Friends Hekp and Support Me a Lot To

Area of Support	*N*	*Minimum*	*Maximum*	*M*	*SD*
Follow my meal plan	208	1.00	6.00	4.21	1.34
Take my medicine	207	1.00	6.00	4.20	1.31
Take care of my feet	206	1.00	6.00	4.23	1.33
Get enough physical activity	204	1.00	6.00	4.15	1.34
Test my sugar	205	1.00	6.00	4.17	1.33
Handle my feelings about diabetes	205	1.00	6.00	4.11	1.36

Nearly half (49.5%, *n* = 103) of AAW reported that other family members provided the most help in caring for their diabetes; and for 17.3% (*n* = 36) of AAW, their spouses provided the most support. Approximately one-fourth (27.4%, *n* = 57) had paid help as reflected in Table 9.

Table 9

Which of The Following Provide The Most Help in Caring for Your Diabetes?

Person Providing Most Help	*n*	*%*
Spouse	36	17.3
Other Family members	103	49.5
Friends	12	5.8
Paid Helper	29	13.9
Other paid health care professional	28	13.5
Total	208	100.0

In the last month, 31.3% (*n* = 65) had no blood sugar (glucose) reactions with symptoms such as sweating, weakness, anxiety, hunger or headaches; however, 45.7% (*n* = 95) had reactions 1-3 times; and 13.5% (*n* = 28) had reactions 4-6 times. See Table 10.

Table 10

How Many Times In the Last Month Have You Had a Low Blood Sugar (glucose) Reaction With Symptoms Such as Sweating, Weakness, Anxiety, Trembling, Hunger or Headache?

	Number of Times	*n*	*%*	*Valid %*	*Cumulative %*
	0 times	65	31.3	31.4	31.4
	1-3 times	95	45.7	45.9	77.3
	4-6 times	28	13.5	13.5	90.8
	7-12 times	9	4.3	4.3	95.2
	more than 12 times	8	3.8	3.9	99.0
	Don’t know	2	1.0	1.0	100.0
	Total	207	99.5	100.0	
Not	Answered	1	0.5		
Total		208	100.0		

During the past year, 31.3% (*n* = 65) of AAW had no severe blood sugar reactions such as passing out or needing help to treat the reaction; however, 37.5% (*n* = 78) had severe reactions 1-3 times; 20.7% (*n* = 43) had severe reactions 4-6 times; and 3.4% (*n* = 7) had severe reactions more than 12 times. See Table 11.

Table 11

How Many Times in the Last Year Have You Had Severe Low Blood sugar Reaction Such As Passing Out or Needing Help to Treat the Reaction?

	Number of Times	*n*	%	*Valid %*	*Cumulative %*
	0 times	65	31.3	31.4	31.4
	1-3 times	78	37.5	37.7	69.1
	4-6 times	43	20.7	20.8	89.9
	7-12 times	12	5.8	5.8	95.7
	More than 12 times	7	3.4	3.4	99.0
	Don’t know	2	1.0	1.0	100.0
	Total	207	99.5	100.0	
Not	Answered	1	0.5		
Total		208	100.0		

During the last month, 28.4% (*n* = 59) did not have high blood sugar symptoms such as thirst, dry mouth and skin, increased sugar in the urine, less appetite, nausea, or fatigue; however, 53.8% (*n* = 112) had symptoms 1-3 days; and 10.1% (*n* = 21) had symptoms 4-6 days. Nearly 3% (*n* = 6) had symptoms more than 12 days. See Table 12.

Table 12

How Many Days in the Last Month Have You Had High Blood Sugar with Symptoms Such As Thirst, Dry Mouth and Skin, Increased Sugar in the Urine, Less Appetite, Nausea, or Fatigue?

	Number of Days	*n*	*%*	*Valid %*	*Cumulative %*
	0 days	59	28.4	28.5	28.5
	1-3 days	112	53.8	54.1	82.6
	4-6 days	21	10.1	10.1	92.8
	7-12 days	7	3.4	3.4	96.1
	More than 12 days	6	2.9	2.9	99.0
	Don't know	2	1.0	1.0	100.0
	Total	207	99.5	100.0	
Not	Answered	1	0.5		
Total		208	100.0		

AAW were asked about the frequency of hospital visits during the past year. The highest mean frequency of hospital visits was for limb amputations (*M* = 5.66, *SD* = 1.06), followed by heart disease (*M* = 5.00, *SD* = 1.74), and kidney disease (*M* = 4.87, *SD* = 1.94).

Table 13

During The Past Year, How Many Times Did You Go To a Hospital for?

Reason for Visit	*N*	*Minimum*	*Maximum*	*M*	*SD*
Kidney disease	206	1.00	6.00	4.87	1.94
Heart disease	203	1.00	6.00	5.00	1.74
Numbness in limbs	206	1.00	6.00	4.45	1.85
Eye sight issues	206	1.00	6.00	4.27	1.91
Limb amputation	204	1.00	6.00	5.66	1.06
Other not related to an accident	205	1.00	6.00	4.45	1.76

Participants were asked to rate the importance of keeping their blood sugar, weight, etc. under control on a Likert scale from strongly disagree (1) to strongly agree (5). Responses in all categories were ranked equally with mean of 4.6, which is between agree (4) and strongly agree (5). See Table 14.

Table 14

I Think It Is Important For Me To …

Aspect of Healthcare	*N*	*Minimum*	*Maximum*	*M*	*SD*
I keep my blood sugar in good control	205	1.00	5.00	4.61	0.85
I keep my weight under control	206	1.00	5.00	4.61	0.82
I do things I need to do for my diabetes (diet, medicine, exercise, etc.)	206	1.00	5.00	4.63	0.76
I handle my feelings (fear, worry, anger) about my diabetes.	205	1.00	5.00	4.63	0.77

AAW were asked about the health benefits of taking the best possible care of diabetes. They responded on a Likert scale from strongly disagree (1) to strongly agree (5) that it would delay or prevent eye problems, kidney problems, foot problems, hardening of the arteries, and heart disease. Responses trended toward strongly agree in the aforementioned areas as presented in Table 15.

Table 15

Taking the Best Possible Care of Diabetes Will Delay or Prevent:

Health Problem	*N*	*Minimum*	*Maximum*	*M*	*SD*
Eye problems	207	1.00	5.00	4.65	0.77
Kidney problems	208	1.00	5.00	4.65	0.78
Foot problems	207	1.00	5.00	4.68	0.71
Hardening of the arteries	208	1.00	5.00	4.64	0.80
Heart disease	208	1.00	5.00	4.65	0.79

Compared to one year ago, 20.7% (*n* = 43) rated their health much better now than a year ago; and 41.8% (*n* = 87) rated their health somewhat better now than a year ago. However, 2.4% (*n* = 5) opined that their health was much worse now than one year ago. See Table 16.

Table 16

Compared To One Year Ago, How Would You Rate Your Health In General Now?

	Health Status	*n*	%	*Valid %*
	Much better now than one year ago	43	20.7	20.8
	Somewhat better now than one year ago	87	41.8	42.0
	About the same	59	28.4	28.5
	Somewhat worse now than one year ago	13	6.3	6.3
	Much worse now than one year ago	5	2.4	2.4
	Total	207	99.5	100.0
Not	Answered	1	0.5	
Total		208	100.0	

Caregiver Status Form

Within the last year, 58.7% (*n* = 122) of AAW have had non-paid caregivers such as friends or family members to assist them with medical care such as daily activities, doctor visits, and medication; whereas 24.5% (*n* = 51) had paid professionals. See Table 17.

Table 17

Within The Last Last Year, Have You Had Someone Who Assisted You with Your Medical Care (such as assistance with daily activities, doctor visits, and/or medication)? (Check all that apply):

Person/Entity Providing Help	*n*	*%*	*Valid %*
I have/had a PAID or PROFESSIONAL caregiver or caregivers (such as nurse, aide, or home attendant)	51	24.5	27.9
I have/had a NON-PAID caregiver or caregivers (such as a friend or family member)	122	58.7	66.7
I have/had additional organized services (such as Meals on Wheels, rides, senior center, or cleaning services)	4	1.9	2.2
I live/have lived in a full-time nursing facility	1	.5	.5
None of the above/don't know	5	2.4	2.7
Total Answered	183	88.0	100.0
Not Answered	25	12.0	
	208	100.0	

When AAW are discharged from the hospital, 36.1% (*n* = 75) will have non-paid caregivers such as friends or family members; to assist them with medical care such as daily activities, doctor visits, and medication; whereas 21.2% (n = 44) will have paid or professional caregivers such as a nurse, aide, or home attendant. See Table 18.

Table 18

When You Are Discharged From the Hospital, Do You Plan to Have Someone Assist You with Your Medical Care (such as assistance with daily activities, doctor visits, and medication)? (Check all that apply):

Help	Person/Entity Providing	*n*	*%*	*Valid %*
	I will have a PAID OR PROFESSIONAL caregiver or caregivers (such as nurse, aide, or home attendant)	44	21.2	24.0
	I will have a NON-PAID caregiver or caregivers (such as a friend or family member)	75	36.1	41.0
	I will have additional organized services (such as Meals on Wheels, senior center, or cleaning services)	2	1.0	1.1
	None of the above/don't know	62	29.8	33.9
	Total	183	88.0	100.0
Not	Answered	25	12.0	
Total		208	100.0	

If AAW planned to have non-paid caregivers such as family members or friends assisting them after discharge, 15.4% (n = 32) disclosed that they would need a lot of assistance; 25.5% (n = 53) would need some assistance, and 1% (n = 2) did not know the degree of assistance they might require. The amount non-paid assistance respondents expected after discharge is presented in Table 19.

Table 19

If a NON-PAID Caregiver Such As a Family Member or Friend Will Assist You After Discharge: How Much Assistance Do You Expect Your Family Member or Friend Will Provide To You?

	Amount of Assistance	*n*	%	*Valid %*
	A Lot	32	15.4	17.6
	Some	53	25.5	29.1
	A Little	25	12.0	13.7
	Don't Know	2	1.0	1.1
	Not applicable	70	33.7	38.5
	Total	182	87.5	100.0
Not	Answered	26	12.5	
Total		208	100.0	

The most frequent primary family member/friend that AAW indicated would assist them included other family members (21.2%, *n* = 44); multiple family members/friends (15.4%, *n* = 32), and son/daughter (13.5%, *n* = 28). The primary family members expected to assist AAW are presented in Table 20.

Table 20

Who Is The Primary Family Member or Friend Who Will Assist You?

	Family Member/Friend	*n*	%	*Valid %*
	Spouse/Partner	27	13.0	14.8
	Son/Daughter	28	13.5	15.3
	Friend	12	5.8	6.6
	Parent	5	2.4	2.7
	Other Family Member	44	21.2	24.0
	Multiple Family Members/Friends	32	15.4	17.5
	Don't know	1	0.5	0.5
	Not applicable	34	16.3	18.6
	Total	183	88.0	100.0
Not	Answered	25	12.0	
Total		208	100.0	

Approximately half (52.4%, *n* = 109) of AAW had female caregivers; 31.3% (*n* = 65) had male caregivers, and 16.3% (*n* = 34) did not answer the question. The non-paid caregivers' ages ranged from 17-79 (*M* = 43.43, *SD* = 12.94). Regarding the race of the non-paid caregivers, 69.2% (*n* = 144) were minorities; 14.9% (*n* = 31) were white/Caucasian; 15.9% (*n* = 33) did not answer the question or either the question did not apply to them.

If participants had caregivers, 45.7% (*n* = 95) had non-paid caregivers to assist them with taking medications, whereas 24% (*n* = 50) had paid caregivers. Regarding arranging doctor visits, 58.2% (*n* = 121) had non-paid caregivers, whereas 25% (*n* = 52) had paid caregivers. Regarding eating or feeding themselves, 16.3% (*n* = 34) had non-paid caregivers and 10.6% (*n* = 22) had paid caregivers. See Table 21.

Table 21

If You Had or Have a Caregiver, Check the Tasks For Which You Receive Assistance From Caregiver(s):

Activity of Daily Living	Paid Care-Giver	Non-paid Caregiver	Not Answered	Total
Taking medications	24%, *n* = 50	45.7%, *n* = 95	30.3%, *n* = 63	208
Arranging visits to the doctor	25%, *n* = 52	58.2%, *n* = 121	16.8%, *n* = 35	208
Transportation to doctor visits	23.1%, *n* = 48	58.7%, *n* = 122	18.3%, *n* = 38	208
Grocery shopping or meal preparation	18.3%, *n* = 38	62.5%, *n* = 130	19.2%, *n* = 40	208
Medical (blood pressure bandages)	19.7%, *n* = 41	46.2%, *n* = 96	34.1%, *n* = 71	208
Dressing or bathing	16.3%, *n* = 34	23.6%, *n* = 49	60.1%, *n* = 125	208
Moving about or walking	10.1%, *n* = 21	24%, *n* = 50	65.9%, *n* = 137	208
Using the bathroom	10.6%, *n* = 22	15.4%, *n* = 32	74%, *n* = 154	208
Eating or feeding self	10.6%, *n* = 22	16.3%, *n* = 34	73.1%, *n* = 152	208
None/Don’t know	2.9%, *n* = 6	6.3%, *n* = 13	90.9%, *n* = 189	208

Research Question

Is there a significant relationship between primary caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status? The research question and related hypotheses were investigated with binomial logistic regression. The dependent variable was health status among African American women diagnosed with type 2 diabetes, which was dichotomized (good to excellent, poor to fair). Prior to the analyses, the residuals were analyzed. A residual is a difference between the observed and the model predicted values of the dependent variable. Standardized residuals that were greater than three standard deviations were excluded after one iteration; after three iterations, an acceptable logistic regression model was generated. After excluding the outlying residuals, a total of 186 cases were analyzed and the full model significantly predicted self-reported health status, X^2=16.281, df= 8, N = 186, p< .039. The model accounted for 12.3% (NagelkerkeR^2) of the variance in self-reported health status. Overall, 82.6% of predictions were accurate. Based on the analysis, caregiver status, and education reliably predicted self-reported health status. The values of the coefficients revealed that having a paid caregiver was associated with a lower odds of having good to excellent healthcare (OR 0.294, p =.004). Similarly, an increase in education by one unit was associated with an increase in the odds of having good to excellent healthcare. The regression coefficients are presented in Table 22.

Table 22.

Regression Coefficients for Caregiver Status and Self-Reported Health Status

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I.for EXP(B)	
							Lower	Upper
Caregiver Status (paid vs unpaid)	-1.225	.429	8.145	1	.004	.294	.127	.681
Marital Status (married vs unmarried)	-.063	.407	.024	1	.878	.939	.423	2.087
Age	.005	.011	.235	1	.628	1.005	.985	1.026
Education			7.152	5	.210			
Eighth grade or less	-.811	.806	1.010	1	.315	.445	.092	2.160
Some high school	.213	.791	.072	1	.788	1.237	.262	5.833
High school graduate	-.201	.721	.078	1	.781	.818	.199	3.360
Some college or technical school	.034	.704	.002	1	.961	1.035	.260	4.115
College Graduate (Bachelor's Degree)	2.116	1.190	3.165	1	.075	8.301	.806	85.464
Graduate degree						1.000		
Constant	1.584	.941	2.834	1	.092	4.876		

Note. a. Variable(s) entered on step 1: Caregiver_Status, Marital_Status, Age, Education.

H_{1a}: stated that there was a relationship between primary caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status. There was a statistically significant relationship between primary caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status $p< .039$. Specifically, having a paid caregiver was associated with a lower odds of having *good* to excellent health (0.294, p = .004). Therefore, $H_{1a:}$ was supported and the null hypothesis was rejected.

Summary

The logistic regression model accounted for 12.3% of the variance in self-reported health status. Overall, 82.6% of predictions were accurate. Based on the analysis, caregiver status reliably predicted self-reported health status. The values of the coefficients revealed that having a paid caregiver was associated with a decrease in the odds of having *good* to excellent health. Implications of these results will be discussed in Chapter Five

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This chapter presents an interpretation of the major findings, limitations of the study, recommendations, social change implications, and conclusion. The purpose of this study was to examine the relationship between caregiver status and self-reported health status; for a sample of 186 African American women (AAW) diagnosed with type 2 diabetes, after accounting for age, education and marital status. In 2014, African American women were at greater risk for type 2 diabetes compared to both the general population and non-Black women. In 2012, type 2 diabetes prevalence for AAW was 14.7% compared to 8.6% for the general population and 6.5% for non-Hispanic White women. AAW comprised 13% of all American women and accounted for more than 50% of all new type 2 diabetes cases annually (CDC, 2014).

Effective glycemic control for those diagnosed with type 2 diabetes requires insulin self-medication compliance, healthy eating habits, and regular physical activity; which frequently require caregiver assistance (Ross, Tildesley, & Ashkenas, 2011). Studies found that supportive family members and caregivers were associated with better medication compliance, improved diet, physical activities, and significantly affects self-reported health (Dunbar et al., 2008).

Communities comprised primarily of low-SES families frequently depended on family members as primary caregivers to assist chronically ill patients with one or more of the following responsibilities: taking prescribed medications, monitoring diet choices, providing transportation for medical appointments, and monitoring glycemic level (Mosca et al., 2012).

This study's finding was small but significant relationship was found between caregiver status and health status for a sample of 186 AAW with type 2 diabetes, after controlling for age, education, and marital status was at $p < .039$. Eight-five (41%) participants reported receiving more than a little assistance from Non-paid caregivers in the form of family members or friends after discharge from a hospital stay, while 44 (21%) relied on a paid caregiver in the study.

Respondents ranged from ages 19-99 ($M = 56.20$, $SD = 19.72$). Regarding marital status, 30.3% ($n = 63$) were never married and 31.3% ($n = 65$) were married. Approximately 15% ($n = 32$) of AAW lived alone and 85% ($n = 176$) lived with one or more people. Regarding educational attainment, 11.5% ($n = 24$) had an eighth grade or less education; 18.3% ($n = 38$) had some high school; 22.6% ($n = 47$) were high school graduates or had their GEDs; 26.0% ($n=54$) has some College or technical school1; 3.5% ($n=28$) College Graduate (bachelor's degree; and 8.5% ($n=17$) Graduate Degree.

More than half (56.7%, $n = 118$) of the participants were disabled, not able to work and 43.3% ($n = 90$) were retired. Concerning self-reported health status, 81.6% ($n = 169$) rated their health status from good to excellent; whereas 18.3% ($n = 38$) rated their health status from poor to fair. Nearly half (49.5%, $n = 103$) of AAW reported that other family members provided the most help in caring for their diabetes; for 17.3% ($n = 36$) of AAW, their spouses provided the most support.

Approximately one-fourth (27.4%, n = 57) had paid help. Within the last year, 58.7% (n = 122) of AAW have had non-paid caregivers such as friends or family members to assist them with medical care such as daily activities, doctor visits, and medication; whereas 24.5% (n = 51) had paid professionals.

When AAW are discharged from the hospital, 36.1% (n = 75) had non-paid caregivers such as friends or family members; to assist them with medical care such as daily activities, doctor visits, and medication; whereas 21.2% (n = 44) had paid or professional caregivers such as a nurse, aide, or home attendant.

If AAW planned to have non-paid caregivers such as family members or friends assisting them after discharge, 15.4% (n = 32) disclosed that they needed a lot of assistances; 25.5% (n = 53) needed some assistance, and 1% (n = 2) did not know the degree of assistance they might require. The most frequent primary family member or friend that AAW indicated would assist them included other family members (21.2%, n = 44); multiple family members/friends (15.4%, n = 32), and son/daughter (13.5%, n = 28).

Approximately half (52.4%, n = 109) of AAW had female caregivers; 31.3% (n = 65) had male caregivers, and 16.3% (n = 34) did not answer the question. Non-paid caregivers’ ages ranged from 19-79 (M = 43.43, SD = 12.94). Regarding the race of the non-paid caregivers, 69.2% (n = 144) were minorities; 14.9% (n = 31) were white or Caucasian; 15.9% (n = 33) did not answer the question or either the question did not apply to them.

If participants had caregivers, 45.7% (n = 95) had non-paid caregivers to assist them with taking medications, whereas 24% (n = 50) had paid caregivers. Regarding arranging doctor visits, 58.2% (n = 121) had non-paid caregivers, whereas 25% (n = 52) had paid caregivers. Regarding eating or feeding themselves, 16.3% (n = 34) had non-paid caregivers and 10.6% (n = 22) had paid caregivers.

Interpretation of Findings

This section is focused on the interpretation of the research question that guides this research study.

Research Questions

Is there a relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status?

Hypothesis

H_{1o}: There is no relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after controlling for age, education, and marital status.

$H_{1}a$: There is a statistically significant relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes after for age, education, and marital status.

A power analysis was conducted with G*Power 3.1(Faul, Erfelder, Lang, & Buchner, 2007). For an odds ratio of 2.0 and a power level of .95, a sample size of 180 participants was required to reach the medium effect size. But, a total of 254 participants started the survey. Of that number, 46 were eliminated for not meeting the study inclusion criteria leaving a sample size of 208.The research question and related hypotheses were investigated with binomial logistic regression. The dependent variable was health status among African American women diagnosed with type 2 diabetes, which was dichotomized (good to excellent, poor to fair). Prior to the analysis, the residuals were analyzed. A residual is a difference between the observed and the model predicted values of the dependent variable. During the analysis, those standardized residuals that were greater than three standard deviations were excluded after one iteration.

After three iterations, (Iteration is the act of repeating a process with the aim of approaching a desired goal, target or result.) an acceptable logistic regression model was generated. After excluding the outlying residuals, a total of 186 cases were analyzed, and the full model significantly predicted self-reported health status, X2=16.281, df = 8, N = 186, p< .039. The model accounted for 12.3% (NagelkerkeR2) of the variance in self-reported health status.

Overall, 82.6% of predictions were accurate. Based on the analysis, caregiver status reliably predicted self-reported health status. The values of the coefficients revealed that having a paid caregiver was associated with a decrease in the odds of having good to excellent health by a factor of 0.294, p = .004. Therefore, H1a: was supported and the null hypothesis was rejected. Similarly, an increase in education by one unit was associated with an increase in the odds of having good to excellent healthcare.

Small positive correlation between caregiver status and health status

Based on the study findings, there is a small but statistically significant relationship between primary caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes; after controlling for age, education, and marital status. Participants with a paid caregiver were slightly more likely to self-report fair or poor health by a factor of 0.294, p =.004. These findings confirmed earlier studies that the presence of a paid caregiver was associated with worse patient clinical outcomes (Mochari-Greenberger, Mosca, Aggarwal, Umann, & Mosca, 2014; Comellas, 2012; Mosca et al., 2011).

Specifically, findings confirmed Mosca et al. (2011), in which a year-long study of 4,058 consecutive patients admitted to a large metropolitan hospital found an association between paid caregivers and poor health outcomes. Mosca et al. (2012) reported the association between paid caregiver status and poor health outcomes after controlling for comorbidity factors, age, gender, and race.

The findings were consistent with Comellas (2012), in which a 1-year observational prospective analysis of 883 adult patients (59% age ≥65 years or older, 61% males and 53% minorities) with diabetes, hospitalized at a university medical center cardiovascular service, part of the Family Cardiac Caregiver Investigation to Evaluate Outcomes (FIT-O) study. The associations of having a caregiver (paid or unpaid) versus not having a caregiver with glycemic control (HbA1C < 7%) were examined and found no significant association between having a caregiver and glycemic control among hospitalized diabetics. The findings was also supported by the research of Mochari-

Greenberger et al. (2014), which was a sample of 665 consecutively admitted cardiac surgery patients as part of the NHLBI-sponsored Family Cardiac Caregiver Investigation To Evaluate Outcomes (FIT-O).

Participants (mean age 65 years; 35% female; 21% racial or ethnic minorities) completed an interviewer-assisted questionnaire to determine caregiver status. Outcomes were documented by a hospital-based information system, demographics, comorbidities, or by electronic records. Associations between caregiving and outcomes were evaluated by logistic regression, adjusted for demographic and comorbidity conditions; found that, having a paid caregiver was significantly associated with rehospitalization or death at 1-year in univariate analysis (OR=2.09; 95%CI=1.18–3.69), informal or paid caregiving was (OR = 1.39; 95% CI=0.94–2.06). Increased odds of rehospitalization or death associated with paid caregiving attenuated after adjustment (OR=1.39; 95%CI=0.74–2.62). Postoperative cardiac patients who had a paid caregiver had longer length-of-stay independent of comorbidity. Demographics and comorbidity explained the increased risk of rehospitalization or death associated with paid caregiving. These data suggest caregiver status assessment may be a simple method to identify cardiac patients at risk for adverse outcome.

The findings of this and other similar studies regarding caregiver, the significant association between caregiver status and poor health outcomes, increased rate of re-hospitalization, or death could have several explanations. The poorer health outcomes associated with caregiver status may have resulted from comorbidity. However, Mosca et al. (2011) and Comellas (2012) reported similar results after controlling for comorbidity.

Moreover, for the sickest participants in the Mosca et al. (2012) study, those with the greatest number of comorbidities, the presence of a paid caregiver was a significant predictor of rehospitalization within one year death, suggesting that factors other than those included in the GHALI Comorbidity Index were responsible for the association. A second explanation for the findings may be that caregivers enable patient access to healthcare providers, and in doing so, increase the number of diagnoses (Mosca et al., 2012).

This suggested that those without a caregiver are similarly unhealthy but have not yet received the news in the form of a diagnosis. A third explanation is that the poorer health outcomes are the result of negative interactions between patients and their caregivers. Either caregiver or interactions have the potential to hinder patient care if there is significant nagging or criticizing about patient care or over-protectiveness (Mosca et al., 2012). Neither gender nor marital status was a predictor of rehospitalization in our study, suggesting that relation influences did not play a significant role.

Essential role of family and informal caregivers

Nearly 75% of study participants reported that their primary caregiver was a spouse, family member, or friend. The primary types of assistance that caregivers provided study participant included instrumental services (cooking, cleaning, and administrative assistance) and, daily living or occupational activities (mobility or moving around, eating and drinking, personal hygiene), and medication administration. These findings are consistent with previous research that indicated non-professionals, such as family members or unpaid caregivers, provide a majority of caregiving annually to type 2 diabetes patients (Haas et al., 2012). For individuals suffering from chronic conditions, research demonstrates that caregiver assistance was associated with improved quality of life. Approximately 25% of study participants received assistance from paid professionals or aides because of quality or financial concerns. Unpaid caregivers represent a large, costeffective source of caregiving and can play a significant role under the chronic care model of healthcare delivery.

Research suggested that glycemic control protocols are more effective when tailored based on ethnic background, gender and age (Misra & Lager, 2009). Other studies suggest that for AAW, the most significant challenge is with exercise levels and healthy diets (Leger, 2010). Cultural barriers exist for AAW regarding type 2 diabetes disease self-management, including lack of education, trepidation regarding the health care system; limited access to the health care system, limited financial resources, and lack of family support (Misra & Lager, 2009).

To leverage the unpaid caregiver resources available to AAW, culturally sensitive interventions are necessary that empower friends and family members that provide caregiving to AAW. Disease management interventions must provide proper support for the patients’ management of the disease, including patient and unpaid caregiver education (Garzmararian, Ziemer, & Barnes, 2009; Reichsman et al., 2009). Research regarding efficacious caregiver intervention is in its infancy, and much work remains to be done to identify what interventions are most effective in empowering unpaid caregivers’ resources to improve health outcomes. Paid and unpaid caregivers are significant, and essential contributors to optimal type 2 diabetes self-care and further research are needed to understand how best to improve mortality and morbidity outcomes (Dunbar et al., 2008).

Significant Comorbidities

Consistent with previous studies on populations diagnosed with type 2 diabetes, study participants reported significant comorbidities. Study participants reported an average of four hospitalizations in the preceding twelve months for one or more of the following conditions: kidney disease, CVD, numbness in limbs, eyesight issues, and limb amputation. These findings were consistent with Mosca et al. (2011), which reported significant comorbidities between type 2 diabetes and CVD, Chronic Renal Failure, Chronic Obstructive Pulmonary Disease, and Coronary Artery Bypass Grafting. The Center for Disease Control and Prevention (2012) statistics reported cardiovascular mortality four times greater for those diagnosed with type 2 diabetes than average.

In Mosca et al. (2012), participants with paid caregivers were the sickest subgroup in the study, after controlling for comorbidity. In the present study, participates with caregivers reported hospitalizations for an average of five comorbidity conditions, including kidney and heart disease. The health condition and comorbidities of study participants were consistent with other research studies on patients diagnosed with type 2 diabetes. These findings underscore the need for active disease management of type 2 diabetes to manage the catastrophic health consequences associated with the disease, particularly for AAW, a population at greater risk for a type 2 diabetes diagnosis.

Ninety-five percent of study participants reported the use of a paid (27.9%) or unpaid (66.7%) caregiver over the preceding twelve months. The study showed that nearly all AAW with type 2 diabetes require paid and unpaid caregivers for: taking medication, medical appointments, transportation, grocery shopping, and home medical monitoring. Study participants showed poor overall health and needed frequent assistance from a caregiver, which most commonly a family member. The study findings support the need for prevention, detection, and treatment of hypoglycemia in the AAW community to spread the information about the risk factors that may lead to complications and discuss interventions to reduce these risk factors. Older AAW with diabetes are known to be at higher risk for poor glycemic control due to the higher number of prescribed medications, and multiple comorbidities (Yaffe et al., 2013). The study highlighted the importance of adequate regulated glycemic control for AAW, including community outreach and support.

Type 2 diabetes is an incurable, progressive disease that disproportionally affects African American women. Early detection and treatment are necessary to avoid fatal complications and extend life. Type 2 diabetes disease management requires daily management of routine patient care in a planned, proactive manner, rather than the current episodic, reactive care to emerging acute disease states (Nolte & McKee, 2008).

Implementation of the CCM, a structured approach that integrates caregiving into proactive disease management, is consistent with daily maintenance necessary to improve self-reported health status. The CCM promotes medication self-management, adherence to healthy eating habits, and a lifestyle including routine physical activity or exercise.

The CCM is an appropriate framework for this study because it incorporates a significant caregiver role in disease management. Disease management protocols for type 2 diabetes suggest an important role for paid and unpaid caregivers in the day-to-day patient care. Interventions include: (a) educating family members on daily self-management activities; (b) integrating family members into daily self-management as unpaid caregivers, and (c) encouraging caregivers to identify available community resources.

Both the daily disease management needs and progression of type 2 diabetes are well known and predictable. While the present study did not support the relationship between caregiver status and self-report health measures, the findings confirm the community need for a transition from reactive disease management initiated by a new symptom, to a proactive system that delivers daily preventive care. Study participants reported frequent hospitalizations for type 2 diabetes and related illnesses and reported poor overall health. The study findings are consistent with comorbidity playing an important role in self-reported health outcomes for AAW diagnosed with type 2 diabetes. Effective glycemic control and daily disease management are necessary to maximize self-reported health and quality of life.

Consistent implementations of CCM principles represent a significant pathway to improving patient's awareness of the potential for self-management to improve health outcomes. AAW deserve particular attention due to their increased risk and their role as a potential caregiver to other family members. Based on the frequency and severity of the health threat that type 2 diabetes represents, there is a critical need for culturally appropriate interventions aimed at improving the health outcome for AAW. Appropriate disease management includes caregiver availability, education, daily reminders, and a shift toward proactive healthcare delivery.

Limitations of the Study

There were numbers of factors that served as limitations to the generalizability of the study findings. First, while self-reported health status was a good predictor of future disability, hospitalization, and mortality, researchers reported a number of known covariates not controlled for by this study, including socioeconomic status, comorbidity, and diabetes disease duration. Second, self-reported health status measures have been shown to have relatively low test-retest reliability and construct reliability.

The limitation was compounded by the use of a single measure of health completed on a single visit. The use of medical records, additional self-report tests, or the survey of a caregiver have the potential to improve the study's validity and reliability. Third, the study sample was limited to AAW diagnosed with type 2 diabetes with access to complete an online survey. The sampling procedure excluded those without access to the internet and those with type 2 diabetes but presently undiagnosed. Finally, the explanatory power of caregiver status to affect self-reported health status could be attributable to an unknown, or unmeasured, covariate.

The limitations to generalizing study findings were addressed several ways. First, the research design used standardized instruments to measure study variables and the sample size was sufficiently powered to yield statistically significant results with a modest effect size. Second, the self-administered surveys were designed for persons reading at the 8th-grade level, above the average for the study population. Despite the efforts to mitigate the study limitations, the study findings might not generalize to other geographic locations, ethnicities, or cultures (Leedy&Ormrod, 2012).

Recommendations

Research on the relationship between caregiver status and health outcomes for type 2 diabetes patients is relatively new. The FIT-O study (Mosca et al., 2012) was the first large-scale study regarding caregiver status and health outcomes. The purpose of the FIT-O study was to evaluate the patterns and characteristics of caregivers among patients who were hospitalized. The present study aimed to further the research on a sample of African American women diagnosed with type 2 diabetes. While it is intuitively appealing that caregivers should be important contributors to health outcomes, mortality and morbidity outcomes, neither study found a positive association between caregivers and improved health outcomes. Both studies found a small but negative effect on the presence of a paid caregiver and poor health outcomes.

Patient outcomes are positively affected by adherence to medication treatment, quality of care, and social support, but the research has not proved these effects. Further research is needed to isolate the effect of caregivers on health outcomes, mortality and morbidity outcomes (Dunbar et al., 2008, Mosca et al., 2012). It seems likely that unmeasured factors unrelated to caregiver status are mediating the effect of caregivers on health outcomes. In the interim, the presence of a paid caregiver could be a unique method of identifying patients at risk of adverse outcomes.

Social change Implications

The purpose of this study was to examine the relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes, after accounting for age, education and marital status. This is because AAW are at higher risk for type 2 diabetes than their Latinos and whites counterparts. This study's contribution to society is the potential to inform the process of designing disease management protocols to reflect AAW and cultural issues and inform the process for determining a treatment protocol to improve self-reported health status for AAW, an underserved population. This study made an original contribution to Public Health by identifying whether the presence of a caregiver affects self-reported health status for AAW with type 2 diabetes. The result of this study shows that there is relationships between caregiver affect self-reported health status for AAW with type 2 diabetes. Public Health leaders and policy makers could be empowered to make informed decisions and develop policies that target educational intervention for caregivers to improve a self-reported health status, and reduce health care costs.

Conclusion

AAW are at higher risk for a type 2 diabetes diagnosis than their white or Latino counterparts. Type 2 diabetes is a chronic, debilitating illness with no cure and comorbidity with CVD and kidney failure. This study found that nearly all AAW participants with type 2 diabetes required the assistance of a caregiver in the preceding twelve months, showed overall poor health, and needed frequent assistance from a caregiver, most commonly a family member. This study confirmed earlier studies that reported a slightly negative association between paid caregiver status and self-reported health outcomes. Redfoot, Feinberg, & Houser (2014) stated that there are declines in the availability of family caregivers which now shows a growing gap for caregivers as Baby Boomer aged.

In 2010, the caregiver support ratio was more than seven potential caregiver for every person in the high-risk years of 80-plus. In 2030, the ratio is expected to decline sharply to 4 to 1, and it is expected to fall further to less than 3 to 1 in 2050. There is a growing need to prepare both current and future caregivers by equipping them with the necessary tools in the prevention and treatment of type 2 diabetes among AAW. Further research is needed to isolate the benefits of caregiving from the comorbidities and confounding variables associated with type 2 diabetes.

References

Aggarwal, B., Liao, M., Christian, A., & Mosca, L. (2009). Influence of caregiving on lifestyle and psychosocial risk factors among family members of patients hospitalized with cardiovascular disease. *Journal of General Internal Medicine, 24*(1), 93-98.

American Association of Retired People. (2009). *Caregiving in the U.S.* Washington, DC: National Alliance for Caregiving and AARP. Retrieved from: http://www.aarp.org/relationships/caregiving/info-12-2009/caregiving_09.html

American Diabetes Association (2014). Economic costs of diabetes in the US in 2012. *Diabetes care*, *36*(4)1033-1046. Retrieved from http://care.diabetesjournals.org/content/36/4/1033.full

American Diabetes Associations (2014). Statistics about Diabetes. Overall Numbers, Diabetes and Prediabetes. Retrieved from http://www.diabetes.org/diabetes-basics/statistics/

American Diabetes Association. (2013). Diagnosis and classification of diabetes mellitus. *Diabetes care*, *36*(Supplement 1), S67-S74.

American Diabetes Association. (2008). Economic costs of diabetes in the US in 2007. *Diabetes care*, *31*(3), 596-615.

August, K. J., & Sorkin, D. H. (2011). Racial/ethnic disparities in exercise and dietary behaviors of middle-aged and older adults. *Journal of General Internal Medicine, 26*(3), 245-250.

Baty, P. J., Viviano, S. K., Schiller, M. R., & Wendling, A. L. (2010). A systematic approach to diabetes mellitus care in underserved populations: Improving care of minority and homeless persons. *American Journal of Medicine. 42*(9), 623-627.

Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. E. (2000). From social integration to health: Durkheim in the new millennium. *Sociology Science and Medicine, 51*(6), 843-857.

Berkman, L. F., Leo-Summers, L., & Horwotz, R. I. (1992). Emotional support and survival after myocardial infarction. *Annals of Internal Medicine, 117*, 1003-1009.

Blazer, D. (1982). Social support and mortality in an elderly community population. *American Journal of Epidemiology, 115*(5), 684-94.

Blumenthal, J. A., Keefe, F. J., Babyak, M. A., Fenwick, C. V., Johnson, J. M., Stott, K., ... & Emery, C. F. (2009). Caregiver-assisted coping skills training for patients with COPD: background, design, and methodological issues for the INSPIRE-II study. *Clinical Trials*, *6*(2), 172-184.

Bodenheimer T, & Laing, B. (2007). The teamlet model of primary care. *Annals of Family Medicine, 5*(5), 457-461.

Brace, N., Kemp, R., & Snelgar, R. (2009) SPSS for psychologists, 4th ed. New York, NY: Routledge.

Cassie, K. M., & Sanders, S. (2008). Familial caregivers of older adults. *Journal of Gerontology and Social Work, 50*(1), 293-320.

Centers for Disease Control and Prevention (2014). Black or African American Populations**.** Atlanta, GA 30333, USA; Office of Minority Health & Health Equity (OMHHE). Retrieved from http://www.cdc.gov/minorityhealth/populations/REMP/black.html

Centers for Disease Control and Prevention (2014) *National diabetes statistics report: Estimates of diabetes and its burden in the United States, 2014*. Atlanta, GA: US Department of Health and Human Services.

Centers for Disease Control and prevention (2014). Basics About Diabetes. Atlanta GA 303333, USA. Retrieved from http://www.cdc.gov/diabetes/consumer/learn.htm#3

Centers for Disease Control and prevention (2014)**.** Division of diabetes translation**.** National Diabetes Statistics Report, 2014. Atlanta GA 303333, USA. Retrieved from http://www.cdc.gov/diabetes/pubs/general14.htm

Centers for Disease Control and Prevention (2012). *Diabetes Report Card 2012.* Atlanta, GA: U.S. Department of Health and Human Services.

Center for Disease Control and Prevention (2012a). Surveillance for Certain Health Behaviors Among States and Selected Local Areas — United States, 2010. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6201a1.htm?s_cid=ss6201a1_w

Centers for Disease Control and Prevention (CDC, 2000; 2012). Diabetes Research and Statistics. Assessed from http://www.cdc.gov/diabetes/consumer/research.htm

Centers for Disease Control and Prevention (2011). *National diabetes fact sheet: General information and national estimates on diabetes in the United States, 2007*. Atlanta, GA: U.S. Department of Health and Human Services.

Codispoti, C., Douglas, M. R., McCallister, T., & Zuniga, A. (2004). The use of a multidisciplinary team care approach to improve glycemic control and quality of life by the prevention of complications among diabetic patients. *The Journal of the Oklahoma State Medical Association*, *97*(5), 201-204.

Comellas, M. (2014). Health outcomes of patients with type 2 diabetes hospitalized with cardiovascular disease: An assessment of caregivers and glycemic control. Columbia University dissertation retrieved from http://gradworks.umi.com/36/21/3621766.html

Dunbar, S. B., Clark, P. C., QuinZn, C., Gary, R. A., & Kaslow, N. J. (2008). Family influences on heart failure self-care and outcomes. *The Journal of cardiovascular nursing*, *23*(3), 258.

Faul, F., Erdfelder, E., Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavioral Research Methods*, *39*(2), 175-191.

Fitzgerald, J., Davis, W., Connell, C., Hess, G., Funnell, M., & Hiss, R. (1996). Development and validation of the Diabetes Care Profile. *Evaluation Health Professionals*, *19*(2):108-30.

Friedmann, E., Thomas, S. A., Liu, F., Morton, P. G., Chapa, D., Gottlieb, S. S., & Sudden Cardiac Death in Heart Failure Trial (SCD-HeFT) Investigators. (2006).

Relationship of depression, anxiety, and social isolation to chronic heart failure outpatient mortality. *American heart journal*, *152*(5), 940-e1.

Garzmararian, J. A., Ziemer, D. C., & Barnes, C. (2009). Perception of barriers to self-care management among diabetic patients, *Diabetes Educator,* 35(5), 778-788.

Gavin, J. R., Fox, K. M., & Grandy, S. (2011). Race/Ethnicity and gender differences in health intentions and behaviors regarding exercise and diet for adults with type 2 diabetes: A cross-sectional analysis. *BMC public health*, *11*(1), 533.

Gregg, E. W., Cheng, Y. J., Saydah, S., Cowie, C., Garfield, S., Geiss, L., & Barker, L. (2012). Trends in Death Rates Among US Adults With and Without Diabetes Between 1997 and 2006 Findings from the National Health Interview Survey. *Diabetes Care, 35*(6), 1252-1257.

Gumbs, J. M. (2012). Relationship between diabetes self-management education and self-care behaviors among African American women with type 2 diabetes. *Journal of Cultural Diversity*, *19*(1), 18-22.

Haas, L., Maryniuk, M., Beck, J., Cox, C. E., Duker, P., Edwards, L., ... & Youssef, G. (2012). National Standards for Diabetes Self-Management Education and Support. *The Diabetes Educator*, *38*(5), 619-629.

House, J. S., Umberson, D., & Landis, K. R. (1988). Structures and processes of social support. *Annual Review of Sociology, 14*, 293-318.

Hwang, B., Fleischmann, K. E., Howie-Esquivel, J., Stotts, N. A., & Dracup, K. (2011). Caregiving for patients with heart failure: Impact on patients' families. *American Journal of Critical Care, 20*(6), 431-441.

Jackson, S. (2011). *Research methods: A modular approach, 2nd ed*. Belmont, CA: Wadsworth/Cengage Learning.

Jamoom, E. W., Horner-Johnson, W., Suzuki, R., Andresen, E. M., Campbell, V. A., & RRTC Expert Panel on Health Status Measurement. (2008). Age at disability onset and self-reported health status. *BMC Public Health*, *8*(1), 1-7.

Jenkins, C., Pope, C., Magwood, G., Vandemark, L., Thomas, V., Hill, K., Linnen, F., Beck, L. S., & Zapka, J. (2010). Expanding the chronic care framework to improve diabetes management: The REACH study. *Program Community Health Partnership, 4*(1), 65-79.

Kim, M., Berger, D., & Matte, T. (2006). *Diabetes in New York City: Public health burden and disparities.* New York, NY: New York City Department of Health and Mental Hygiene.

Knodel, J., Kespichayawattana, J., Saengtienchai, C., &Wiwatwanich, S. (2010). The role of parents and family members in ART treatment adherence: Evidence from Thailand. *Research on Aging,* 32, 19-39.

Krishnan, S., Cozier, Y. C., Rosenberg, L., & Palmer, J. R. (2010). Socioeconomic status and incidence of type 2 diabetes: results from the Black Women's Health Study. *American Journal of Epidemiology*, 171(5), 564-570.

Leedy, P., Ormrod, J. (2012). *Research: Planning and Design (10th Edition)*. Pearson: London, England.

Leger, E. (2010). Prevalence of Diabetes in African-American Communities: Risk Factors and Prevention as a Social Disease.

Leger, E. (2010). *Prevalence of diabetes in African-American communities: Risk factors and prevention as a social disease.* Retrieved fromhttp://www.brooklyn.cuny.edu/pub/departments/bcurj/pdf/LegerEleonorART.pdf

Levine, C., Halper, D., & Peist, A. (2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Affairs, 29*,116-124.

Liao, Y., Bang, D., Cosgrove, S., Dulin, R., Harris, Z., Taylor, A., ... & Giles, W. (2011). Surveillance of health status in minority communities-Racial and Ethnic Approaches to Community Health Across the US (REACH US) Risk Factor Survey, United States, 2009. *MMWR. Surveillance summaries: Morbidity and mortality weekly report. Surveillance summaries/CDC*, *60*(6), 1-44.

Lysy, Z., Booth, G. L., Shah, B. R., Austin, P. C., Luo, J., & Lipscombe, L. L. (2013). The impact of income on the incidence of diabetes: a population-based study. *Diabetes research and clinical practice*, *99*(3), 372-379.

Mann, D. M., Ponieman, D., Leventhal, H., & Halm, E. A. (2009). Misconceptions about diabetes and its management among low-income minorities with diabetes. *Diabetes Care, 32*(4), 581-593.

McCleary, J. V. (2011). Health literacy and its association with diabetes knowledge, self-efficacy and disease self-management among African Americans with diabetes mellitus. *ABNF Journal, 22*(2), 25-32.

Mezuk, B., Eaton, W. W., Albrecht, S., & Golden, S. H. (2008). Depression and type 2 diabetes over the lifespan: A meta-analysis. *Diabetes Care, 31*(12), 2383-2390.

Misra, R., & Lager J. (2009). Ethnic and gender differences in psychosocial factors, glycemic control, and quality of life among adult Type II diabetic patients. *Journal of Diabetes and its Complications, 23*(1), 54-64.

Mochari-Greenberger, H., Terry, M. B., & Mosca, L. (2011). Sex, age, and race/ethnicity do not modify the effectiveness of a diet intervention among family members of hospitalized cardiovascular disease patients. *Journal of Nutrition Education and Behavior, 43*(5), 366-373. doi: 10.1016/j.jneb.2011.01.014.

Mochari-Greenberger, H., Mosca, M., Aggarwal, B., Umann, T., &Mosca, L. (2014). Caregiver Status: A Simple Marker to Identify Patients at Risk for Longer Post-Operative Length of Stay, Rehospitalization or Death. *The Journal of cardiovascular nursing*, *29*(1), 12.

Montori, V. M., & Fernandez-Balsells, M. (2009). Glycemic control in type 2 diabetes: time for an evidence-based about-face. *Annals of internal medicine*, *150*(11), 803-808

Mosca, L., Aggarwal, B., Mochari-Greenberger, H., Liao, M., Blair, J., Cheng, B., ... & Umann, T. (2012). Association between having a caregiver and clinical outcomes 1 year after hospitalization for cardiovascular disease. *The American journal of cardiology*, *109*(1), 135-139.

Mosca, L., Benjamin, E. J., Berra, K., Bezanson, J. L., Dolor, R. J., Lloyd-Jones, D. M., ... & Wenger, N. K. (2011). Effectiveness-based guidelines for the prevention of cardiovascular disease in women—2011 update: a guideline from the American Heart Association. *Journal of the American College of Cardiology*, *57*(12), 1404-1423.

Nolte, E., & McKee, M. (Eds.). (2008). *Caring for people with chronic conditions: a health system perspective*. McGraw-Hill Education (UK).

Norris, S. L., Nichols, P. J., Caspersen, C. J., Glasgow, R. E., Engelgau, M. M., Jack, L., ... & Task Force on Community Preventive Services. (2002). Increasing diabetes self-management education in community settings: a systematic review. *American journal of preventive medicine*, *22*(4), 39-66.

Osborn, C. Y., Cavanaugh, K., Wallston, K. A., Kripalani, S., Elasy, T. A., Rothman, R. L., ... & White, R. O. (2011). Health literacy explains racial disparities in diabetes medication adherence. *Journal of Health Community, 16*(3), 268-278.

Redfoot, D., Feinberg, L, & Houser, A. (2013). The Aging of the Baby Boom and the Growing Care Gap: A look at future decline in the availability of Family

Caregivers (Washington, D.C.: AARP Public Policy institute, August 2013). Retrieved from www.aarp.gov/research/ppi

Reichsman, A., Werner, J., Cella, P., Bobiak, S., &Stange, K. (2009). Opportunities for improved diabetes care among patients of safety net practices: A Safety Net Providers' Strategic Alliance study. *Journal of the National Medical Association*, *101*(1), 4-11.

Robert Wood Johnson Foundation (RWJF). (2009). *New Health Partnerships: Improving Care by Engaging Patients.* Institute for Healthcare Improvement. Retrieved from http://www.improvingchroniccare.org/index.php?p=The_Chronic_CareModel&s=2

Rolley, J., et al. (2010). The caregiving role following percutaneous coronary intervention. *Journal of Clinical Nursing, 20*(1), 227-235.

Ross, S. A., Tildesley, H. D., &Ashkenas, J. (2011). Barriers to effective insulin treatment: the persistence of poor glycemic control in type 2 diabetes. *Current Medical Research and Opinion, 27*(3), 13-20.

Simmons, L., Baker, N., Schaefer, J., Miller, D., & Anders, S. (2009). Activation of patients for successful self-management. *Journal of Ambulatory Care Management,* 32(1):16-23.

Sinclair, A. J., Armes, D. G., Randhawa, G., & Bayer, A. J. (2010). Caring for older adults with diabetes mellitus: Characteristics of caregivers and their prime roles and responsibilities. *Diabetic Medicine Journal, 27*(9), 1055-1059.

Tabachnick, B., & Fidell, L. (2001). *Using multivariate statistics (4th ed.).* Boston: Allyn and Bacon.

Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health, 97*(2), 224-228.

Thorpe, C. T., Fahey, L. E., Johnson, H., Deshpande, M., Thorpe, J. M., & Fisher, E. B. (2012). Facilitating healthy coping in patients with diabetes a systematic review. *The Diabetes Educator*, 0145721712464400.

Thorpe Jr, R. J., Koster, A., Bosma, H., Harris, T. B., Simonsick, E. M., van Eijk, J. T. M., ... & Kritchevsky, S. B. (2012). Racial differences in mortality in older adults: factors beyond socioeconomic status. *Annals of Behavioral Medicine*, *43*(1), 29-38.

Trivedi, R. B., Bryson, C. L., Udris, E., & Au, D. H. (2012). The influence of informal caregivers on adherence in COPD patients. *Annals of Behavioral Medicine*.

Tsai, A., Morton, S., Mangione, C., & Keeler, E. (2005). Meta-Analysis of Interventions to Improve Care for Chronic Illnesses. *American Journal of Managed Care*, 11(8): 478–488.

Wang, J., Kumiko, I., Engelgau, M. M., Geiss, L. S., Wen, C., & Zhang, P. (2009). Secular trends in diabetes-related preventable hospitalizations in the United States, 1998-2006. *Diabetes Care, 32*(7), 1213-1217. doi: 10.2337/dc08-2211.

Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J., & Bonomi, A. (2008). Improving chronic illness care: Translating evidence into action. Health Affairs, 20, 64-78.

Whittemore, R., & Dixon, J. (2008). Chronic illness: The process of integration. *Journal of Clinical Nursing,* 17, 17B, 177-187.

Winham, D., & Jones, K. (2011). Knowledge of young African American adults about heart disease: a cross-sectional survey. *BMC Public Health*, *11,* 248-252.

Wu, L., Forbes, A., Griffiths, P., Milligan, P., & While, A. (2010). Telephone follow-up to improve glycaemic control in patients with type 2 diabetes: systematic review and meta-analysis of controlled trials. *Diabetic Medicine*, *27*(11), 1217-1225.

Wu, J., Lennie, T., Chung, M., Frazier, S., Dekker, R., & Biddle, M. (2012). Medication adherence in patients who have heart failure: a review of the literature. *Nursing Clinic North America*, 43(1):133-53; vii-viii.

Yaffe, K., Falvey, C., Hamilton, N., Harris, T., Simonsick, E., et al. (2013). Association between hypoglycemia and dementia in a biracial cohort of older adults with diabetes mellitus. *JAMAInternal Medicine*, 173(3):1300–1306.

Yates, D., Moore, M., & McCabe, G. (1999). *The Practice of Statistics (1st Ed.).* New York: W.H. Freeman.

Zhou, Q. P., & Oh, K. M. (2012). Comparison of lifestyle behaviors and related factors between Asian American and White adults with prediabetes. *Nursing Health Science, 14*(1), 58-66.

Zhou, Q. P., Remsburg, R., Caufield, K., & Itote, E. W. (2012). Lifestyle behaviors, chronic diseases, and ratings of health between black and white adults with pre-diabetes. *The Diabetes Educator, 38*(2), 219-22

Appendix A: Consent Form

You are invited to take part in a research study of African American women suffering from type 2 diabetes. The researcher is inviting African American women between the ages of 18 or older, Diagnosed with type 2 diabetes, no longer working due to illness or retirement, and have either a paid or unpaid caregiver to be in the study. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part. This study is being conducted by a researcher named Phanta S. Sackor, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to examine the relationship between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes, after accounting for age, education and marital status. The study will address a gap in the literature regarding the relationship between care giving status and self-reported health status for a sample of AAW diagnosed with type 2 diabetes. The study’s contribution to society is the potential to inform the process of designing disease management protocols to reflect AAW and cultural issues.

Procedures:

If you agree to be in this study, you will be asked to:

- Sign a consent form before you can view and complete the surveys.
- You will complete two surveys. Diabetes care profile (DCP) and the caregiver status form,
- Survey Monkey’s online portal will be used for both surveys ,

- It will take 30minutesto complete the surveys

If you agree to be in this study, you will be asked to ccomplete two surveys. Diabetes care profile (DCP) and the caregiver status form,

It will take 30 minutes to complete the surveys.

Here are some sample questions:

I. Study questions include multiple choice and 5-point Leikert scale questions using *strongly disagree, somewhat agree, neutral, somewhat agree and strongly agree*, corresponding to one through five, respectively

II. If you had/have, caregivers check the task for which you receive assistance from your caregiver(s).

Task		**Assistance from**
a)	*Taking medication*	*Paid/ unpaid*
b)	*Arranging visits*	*Paid/ unpaid*
c)	*Dressing/bathing*	*Paid/ unpaid*

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at Survey Monkey will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as becoming stress or upset about your diabetes statues. Being in this study would not pose risk to your safety or wellbeing. There are no particular direct benefits to the individual; but the study will make an original contribution to Public Health by identifying whether the presence of a caregiver affects self-reported health status for AAW with type 2 diabetes.

Public Health leaders and policy makers could be empowered to make informed decisions and develop policies that target educational intervention to caregivers to improve self-reported health status, and reduce health care costs.

Payment:

Participants will be volunteers and will receive no remuneration or benefit from participating in this research project.

Privacy:

Any information you provide will be kept confidential and Anonymous. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by moving Data generated on a computer to a detachable USB external storage drive and deleted from the computer, eliminating physical access to the data from a network intrusion. The information you provide will not be used for any purposes other than research as required by the university. All Data will be kept for a period of at least 5 years, and eventually destroyed.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via email at phanta.sackor@waldenu.edu or by cell phone at 240-246-5934. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 001-612-312-1210 or email address irb@waldenu.edu). Walden University's approval number for this study is **11-20-14-0225763** and it expires on **November 19, 2015.**

Please print a copy of the consent form.

Statement of Consent:

I have read the above information, and I feel I understand the study well enough to make a decision about my involvement. By clicking the link below, I understand that I am agreeing to the terms described above.

Appendix B: Diabetes Care Profile

Michigan Diabetes
Research and Training Center
DCP2.0

Please answer each of the following questions by filling in the blanks with the correct answers or by choosing the single best answer.

Note: For this survey, a Health Care Provider refers to a doctor, nurse practitioner,
or physician assistant.

Q1. Age: __ __years old

Q2. What year were you first told you had diabetes? (Please enter the year) __ __ __ __

Q3. What is your marital status? (check one box)

☐1 Never married
☐2 Married
☐3 Separated/Divorced
☐4 Widowed
☐5 Living with a partner

Q4. How many people live with you? (check one box)

☐0 I live alone
☐1 1 person
☐2 2 people
☐3 3 people
☐4 4 people
☐5 5 or more

Q5. How much schooling have you had? (Years of formal schooling completed)

(check one box)

☐1 8 grades or less
☐2 Some high school
☐3 High school graduate or GED
☐4 Some college or technical school
☐5 College graduate (bachelor’s degree)
☐6 Graduate degree

Q6. Which of the following best describes your current employment status? (check one box)

☐1 Retired
☐2 Disabled, not able to work
☐9 Something else? (Please specify): ________________________

Q7. Do you test your blood sugar? (check one box)

☐1 No ☐2 Yes → Q7a. How many days a week do you test your blood sugar?

_____ (days / week)

↓

Q7b. On days that you test, how many times do you test your blood sugar?

_____ (times / day)

↓

Q7c. Do you keep a record of your blood sugar test results? (check one box)

☐1 No ☐2 Yes

Q8. In general, would you say your health is: (check one box)

☐1	☐2	☐3	☐4	☐5
Excellent	Very Good	Good	Fair	Poor

Q9. I **want** a lot of help and support from my family or friends in:
(circle one answer for each line)

	Strongly Disagree	**Somewhat Disagree**	**Neutral**	**Somewhat Agree**	**Strongly Agree**	**Does Not Apply**
a) following my meal plan.	1	2	3	4	5	N/A
b) taking my medicine.	1	2	3	4	5	N/A
c) taking care of my feet.	1	2	3	4	5	N/A
d) getting enough physical activity.	1	2	3	4	5	N/A
e) testing my sugar.	1	2	3	4	5	N/A
f) handling my feelings about diabetes.	1	2	3	4	5	N/A

Q10. **<u>More than 50% of the time</u>** my family or friends help and support me a lot to:

(circle one answer for each line)

	Strongly Disagree	**Somewhat Disagree**	**Neutral**	**Somewhat Agree**	**Strongly Agree**	**Does Not Apply**
a) follow my meal plan.	1	2	3	4	5	N/A
b) take my medicine.	1	2	3	4	5	N/A
c) take care of my feet.	1	2	3	4	5	N/A
d) get enough physical activity.	1	2	3	4	5	N/A
e) test my sugar.	1	2	3	4	5	N/A
f) handle my feelings about diabetes.	1	2	3	4	5	N/A

Q11. Which of the following provide the **most** help in caring for your diabetes? (check only one box)

☐1 Spouse
☐2 Other family members
☐3 Friends
☐4 Paid helper
☐5 Other paid health care professional
☐6 None

Q12. How many **times** in the last **month** have you had a **low blood sugar** (glucose) reaction with symptoms such as sweating, weakness, anxiety, trembling, hunger or headache?

☐1 0 times
☐2 1-3 times
☐3 4-6 times
☐4 7-12 times
☐5 More than 12 times
☐6 Don't know

Q13. How many **times** in the last **year** have you had **severe low blood sugar** reactions such as
passing out or needing help to treat the reaction?

☐1 0 times
☐2 1-3 times
☐3 4-6 times
☐4 7-12 times
☐5 More than 12 times
☐6 Don't know

Q14. How many **days** in the last **month** have you had **high blood sugar** with symptoms such
as thirst, dry mouth and skin, increased sugar in the urine, less appetite, nausea, or
fatigue?

☐1 0 days
☐2 1-3 days
☐3 4-6 days
☐4 7-12 days
☐5 More than 12 days
☐6 Don’t know

Q15.	During the past year**, how many times did you go to a hospital** for: (circle one answer for each line)						
	a) kidney issues	1	2	3	4	5	0
	b) heart issues	1	2	3	4	5	0
	c) numbness in limbs	1	2	3	4	5	0
	d) eye sight issues	1	2	3	4	5	0
	e) limb amputation	1	2	3	4	5	0
	f) other not related to an accident	1	2	3	4	5	0

Q16. I think it is important for me to: (circle one answer for each line).	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
a) I keep my blood sugar in good control.	1	2	3	4	5
b) I keep my weight under control.	1	2	3	4	5
c) I do the things I need to do for my diabetes (diet, medicine, exercise, etc.).	1	2	3	4	5
d) I handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

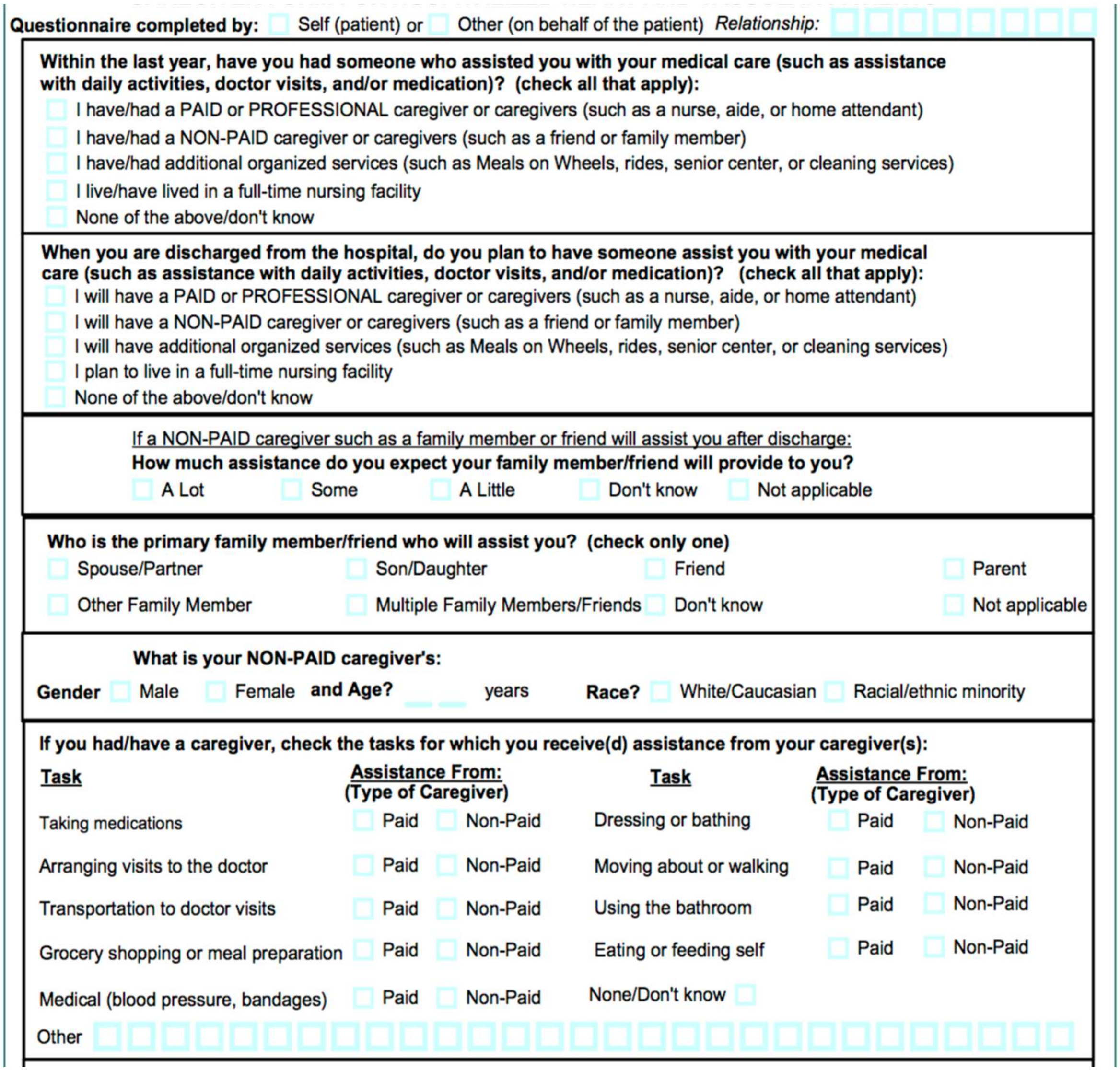
Q17. Taking the best possible care of diabetes will delay or prevent:	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
a) eye problems	1	2	3	4	5
b) kidney problems	1	2	3	4	5
c) foot problems	1	2	3	4	5
d) hardening of the arteries	1	2	3	4	5
e) heart disease	1	2	3	4	5

Q18. Compared to one year ago, how would you rate your health in general now?

(check one box)

☐1 Much better now than 1 year ago
☐2 Somewhat better now than 1 year ago
☐3 About the same
☐4 Somewhat worse now than 1 year ago
☐5 Much worse now than 1 year ago

Appendix C: Caregiver Status Form



Questionnaire completed by: ☐ Self (patient) or ☐ Other (on behalf of the patient) *Relationship:* ☐☐☐☐☐☐☐☐

Within the last year, have you had someone who assisted you with your medical care (such as assistance with daily activities, doctor visits, and/or medication)? (check all that apply):

☐ I have/had a PAID or PROFESSIONAL caregiver or caregivers (such as a nurse, aide, or home attendant)
☐ I have/had a NON-PAID caregiver or caregivers (such as a friend or family member)
☐ I have/had additional organized services (such as Meals on Wheels, rides, senior center, or cleaning services)
☐ I live/have lived in a full-time nursing facility
☐ None of the above/don't know

When you are discharged from the hospital, do you plan to have someone assist you with your medical care (such as assistance with daily activities, doctor visits, and/or medication)? (check all that apply):

☐ I will have a PAID or PROFESSIONAL caregiver or caregivers (such as a nurse, aide, or home attendant)
☐ I will have a NON-PAID caregiver or caregivers (such as a friend or family member)
☐ I will have additional organized services (such as Meals on Wheels, rides, senior center, or cleaning services)
☐ I plan to live in a full-time nursing facility
☐ None of the above/don't know

If a NON-PAID caregiver such as a family member or friend will assist you after discharge:
How much assistance do you expect your family member/friend will provide to you?
☐ A Lot ☐ Some ☐ A Little ☐ Don't know ☐ Not applicable

Who is the primary family member/friend who will assist you? (check only one)
☐ Spouse/Partner ☐ Son/Daughter ☐ Friend ☐ Parent
☐ Other Family Member ☐ Multiple Family Members/Friends ☐ Don't know ☐ Not applicable

What is your NON-PAID caregiver's:
Gender ☐ Male ☐ Female **and Age?** __ __ years **Race?** ☐ White/Caucasian ☐ Racial/ethnic minority

If you had/have a caregiver, check the tasks for which you receive(d) assistance from your caregiver(s):

Task	**Assistance From:** (Type of Caregiver)	**Task**	**Assistance From:** (Type of Caregiver)
Taking medications	☐ Paid ☐ Non-Paid	Dressing or bathing	☐ Paid ☐ Non-Paid
Arranging visits to the doctor	☐ Paid ☐ Non-Paid	Moving about or walking	☐ Paid ☐ Non-Paid
Transportation to doctor visits	☐ Paid ☐ Non-Paid	Using the bathroom	☐ Paid ☐ Non-Paid
Grocery shopping or meal preparation	☐ Paid ☐ Non-Paid	Eating or feeding self	☐ Paid ☐ Non-Paid
Medical (blood pressure, bandages)	☐ Paid ☐ Non-Paid	None/Don't know ☐	

Other ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Appendix D: Study Recruitment Letter

I am a PhD student at Walden University and currently seeking African American women, between the ages of 18 years or older, diagnosed with type 2 diabetes, and have either a paid giver or unpaid caregiver to participate in a research study on Caregiver Status and Self-Reported Health Status. Participants self-reported health status and caregiver status will be evaluated using anonymous online surveys that can be completed in approximately 30 minutes.

There will be no treatment involved; if one chooses to participate, the only requirement is to complete the online surveys. The purpose of this study is to identify new relationships between caregiver status and self-reported health status among African American women diagnosed with type 2 diabetes that could lead to interventions to help reduce or prevent type 2 diabetes. No compensation is available; however, participants often comment that they enjoy being a part of research studies because their input will help reduce excess type 2 diabetes among this underserved population.

Interested participants can log on to a portal at surveymonkey.com to participate in the study. Participation will be anonymous; no personally identifiable information is required. Please follow instructions and complete the survey.