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Charlene Sue Aaron
University of Iowa

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THE SELF-MANAGEMENT OF DIABETES IN OLDER AFRICAN AMERICAN
WOMEN CAREGIVERS OF PERSONS WITH DEMENTIA

by

Charlene Sue Aaron

A thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Nursing
in the Graduate College of
the University of Iowa

May 2014

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CERTIFICATE OF APPROVAL

PH.D. THESIS

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To my husband,
for all you've done

It had long since come to my attention that people of
accomplishment rarely sat back and let things happen to them.
They went out and happened to things.

Leonardo da Vinci

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Thanks to my professors, family, and especially, my mom.

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CHAPTER I

INTRODUCTION

Statement of the Problem

Little is known about the impact of dementia caregiving on self-management of chronic conditions even though self-management and caregiving has been studied extensively. Even less is known about the effects of caregiving of persons with dementia on self-management of chronic conditions among African American women. Many older African American women provide care for persons with dementia with little or no support due to their inherent generational practice of taking care of aging family members rather than sending them to a nursing home and their reluctance to share their family member has dementia (Gerdner, Tripp-Reimer, & Simpson, 2007), the dementia caregiving may greatly impede the management of their own chronic illnesses. Diabetes provides a chronic illness model from which to study the health effects of dementia caregiving on self-management in this vulnerable population. According to the ADA (2011), diabetes is a chronic condition that is two to six times more prevalent in African Americans than in Whites. Diabetes is especially problematic for African Americans because they suffer more morbidity and mortality from the condition (Centers for Disease Control and Prevention, 2011).

According to the American Diabetes Association (ADA) (2011), diabetes is especially detrimental for African American females over age 55 that are at risk for complications from diabetes. One in three women with diabetes will die of heart disease compared to one in nine dying of breast cancer. African Americans are almost 50 percent more likely to develop diabetic retinopathy as non-Hispanic whites. Also, African

Americans are 2.6 to 5.6 times more likely to suffer from kidney disease and are 2.7 times more likely to suffer from lower-limb amputations (ADA, 2012).

Complications from diabetes can lead to decreased independence and diminished quality of life due to vision impairment, fatigue, infection and kidney failure (Araki & Ito, 2009) which likely leads to decreased functional ability and increased mortality for older African American women with the disease (Shenolikar et al., 2006; Trinacty, Adams, & Soumerai et al., 2007).

In addition to experiencing an increased prevalence of, and complications related to, diabetes, African American women age 55 and older are also more likely to be in the role of caring for a loved one with dementia (National Alliance for Caregiving/AARP, 2009). This role, which requires providing 24 hour surveillance, nursing care, and behavior management (Teri, Lodgson, Uomoto, & McCurry, 1997; National Alliance for Caregiving/AARP, 2009), may be at odds with the many self-care activities required to successfully manage their own diabetes (e.g. eating a prescribed diet, exercising regularly, taking medications, and routinely checking blood glucose. The regimented behavior required for diabetes self-management is difficult for those without other responsibilities, but when faced with the additional responsibility of caring for a relative with dementia, the essential tasks of dual necessity compete with each other (Knowler et al., 2009).

Dementia care is more challenging than caring for a person with physical deficits alone. The stress of providing 24-hour care for a person with dementia is complicated by the development of episodes of problematic behaviors when the person becomes increasingly agitated, stressed, or disoriented. Behavioral problems are common,

appearing in up to 67% of care recipients upon diagnosis (Torti, Gwyther, Reed, et al. 2004) in approximately 65% of persons who are institutionalized (Schulz, Boerner, Shear, et al. 2006) and between 70% and 90% of persons with advanced dementia (Adams, Aranda, Kemp, et al. 2002; Coon, Williams, Moore, Edgerly, Steinback, & Feigenbaum, 2004). The care recipient's behaviors worsen with disease progression as the person becomes more dependent and may exhibit psychotic features of dementia such as hallucinations and delusions (Rayner, O'Brien & Schoenbachler, 2006). The demands of dementia caregiving may intensify near the end of life. According to Buhr, Kuchibhatla & Clipp (2006); Hooker et al (2002) and Schulz et al (2006), 59% of caregivers stated in the year before their family member died, they felt as though they were on duty 24 hours a day. Seventy-two percent of the caregivers felt relief when their family member died. Pinqart and Sorensen, 2007; Sorensen, Pinqart, & Duberstein, 2002; Woolf, (2008) have studied the emotional and physical, and financial ramifications of caring for family members with dementia. The findings support a relationship between caregiver's worse physical health conditions as the care recipient's behaviors increase.

Challenging behaviors can have a profound effect on caregivers, and these secondary symptoms are the most stressful to manage from a caregiving perspective (Bell, Araki, & Neuman 2001; Covinsky, Newcomer, Fox, Wood & Sands 2003; Croog, Burleson, Sudilovsk, & Baume, 2006). Caregiving has all the components of a chronic stress experience. It results in physical and psychological strain over extended periods of time and comes with high levels of unpredictability and uncontrollability. The time intensity of dementia caregiving puts secondary stress on the family due to work and family relationships, and requires much vigilance (Schulz & Sherwood, 2008).

Some research has focused on self-management of diabetes among African American women (Cagle, Appel, Skelly, & Carter-Edwards, 2002; Carthron, et al., 2010; Chelbowy, Hood, & LaJoie, 2010; Jenkins, et al., 2011; Ory, 2008; Skelly, et al., 2005b; Wallace, Carlson, Malone, Joyner, & DeWalt, 2010). The problem is the impact of caregiving, a common responsibility of African American Women, on diabetes self-management is lacking. The purpose of this exploratory study was to generate hypotheses about the relationships among caregiving performance difficulty, caregiving intensity, diabetes self-management, and glycemic status among older African American women who are caring for an older person with dementia.

Specific Aims

Aim One: Describe the amount of variation in diabetes self-management activities explained by caregiving performance difficulty, caregiving intensity, and caregiver demographics (i.e., age, education, income, years with diabetes, diet only, medication, glucose testing routine, caring for children, caring for grandchildren, number of co-morbidities of the caregiver).

Aim Two: Describe the amount of variation in relationship between glycemic control (i.e., HgA1c \leq 7% and $>$ 7%) and two diabetes self-management activities (i.e., diet and exercise).

Significance and Innovativeness

The significance of the study is plentiful. First, it helps fill the gap in the literature in this understudied area of older African American women with diabetes who are caregivers of persons with dementia. Second, researchers can have a better understanding of the challenges to self-management at specific levels of dementia caregiving. This

knowledge is important for this population because of the prevalence of African American women with diabetes and the prevalence of their dementia caregiving. The third point of significance is learning more about the self-management of diabetes in African American women who also provide care to persons with dementia will provide more substance with evidence for the state of the science in African American women's health. Finally, by providing the beginning basis for the development and testing of nursing interventions for this population, the findings will contribute to narrowing the wide range of health disparities in older African American women with diabetes with dual responsibilities, with high potential to markedly reduce the costs of health care by reducing health care costs of treating current adverse effects on the health of the caregiver and the loss of the caregivers' capacity to continue to care for their family member with dementia.

Conceptual Definitions

Diabetes Self-Management Activities are defined as selected activities to maintain glycemic control.

Caregiving Performance Difficulty is described as emotional, physical, or financial barriers contributing to caregiver burden.

Caregiving Intensity is defined as levels of caregiving dedicated to providing supervision, surveillance, care assistance with ADLs, behavior management and memory stimulation, and meeting other care needs of a person with cognitive deficits.

Glycemic Status is defined as 7% or less glycosylated hemoglobin.

Demographics are defined as the characteristics of an individual and may include age, income, education, years with diabetes, the use of medications, or diet only, glucose

testing routine, years caring for a person with dementia, caring for children, caring for grandchildren, and caregiver comorbidities.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

This chapter will include a review of the literature that forms the background for the dissertation study. Literature reviewed and summarized includes prevalence reports of diabetes and dementia in African American population research on diabetes self-management, and how the self-management of diabetes occurs in older African American women who are providing care to family members with dementia. Barriers to self-management of diabetes for older African American women, including access to health care services, and low socioeconomic status will be explored (Cagle et al., 2002). Those barriers as well as facilitators to self-management of diabetes will be included in the review, as they relate to African American women caring for family members with dementia, caregiving intensity and glycemic status.

Diabetes, Incidence, Disease Process Progression, with Emphasis on African American Populations

Type 2 diabetes mellitus (T2DM) is associated with insufficient insulin, and or insulin resistance (Chelbowy & Wagner, 2005). T2DM is caused by a combination of insulin resistance and a defect in beta cell secretion. With time, the progressive beta-cell dysfunction can develop and lead to complete insulin deficiency, which results in inability to maintain glycemic control (American College of Physicians, 2007). Most patients with type 2 diabetes are obese or have abdominal obesity. Approximately 20% of patients with newly diagnosed type 2 diabetes already have chronic microvascular

complications of the disease leading to coronary artery disease or peripheral vascular disease at presentation (American College of Physicians, 2007).

Long-term poor glucose control impacts cognitive function and puts older adults with diabetes at risk for infection (Araki & Ito, 2009). The guidelines for improving the care of older adults with diabetes are supported with literature from Gao et al., (2008) who found in people 65 and older that A1C levels of 7.0% or above had a high risk of cardiovascular mortality and dementia compared with older adults with A1C levels of 3.7-6.9.

However, strict control also increases some risks. Hypoglycemia or low blood sugar has been attributed to increased incidences of falls in the elderly using insulin (Nelson et al., 2007). According to Nelson et al., (2007) people with diabetes aged 75 and above are at increased risk for falls when their A1C is 6.0% or less, regardless of frailty status likely because atypical hypoglycemia presents symptoms such as: double vision, dizziness, unsteadiness, and poor coordination (Jaap et al. 1998). Because of the chance for hypoglycemia and injury, elderly people with diabetes who are well-functioning and free of multiple morbidities are best controlled with A1C levels between 6.0 and 7.0% (Strachen, Deary, Ewing, & Frier, 2000).

Type 2 Diabetes mellitus (T2DM) is an epidemic among African Americans who are twice as likely to have diabetes, than their White counterparts (American Diabetes Association (ADA) 2011). African Americans also experience more complications from diabetes than Whites (ADA, 2009). There is a higher prevalence of diabetes in African American women than non-Hispanic Whites and the incidence increases with age (ADA, 2011). Obesity is associated with diabetes and hypertension. Fifty- three percent of

African American women are obese (Warren, Wilcox, Dowda, & Baruth, 2012). According to the Centers for Disease Control and Prevention (2011) African Americans are more likely to develop T2DM if they are 45 years of age or older, overweight, hypertensive, and have a family history of diabetes. One in five African American women over age 55 has diabetes (ADA, 2011). The African American Community Health Advisory Committee (2009) noted that although nearly 3 million African Americans have diabetes, half of these people do not know it.

Cagle et al., (2002) found many African American women admitted to ignoring the symptoms of diabetes and are extremely vulnerable to developing complications from diabetes. In addition, amputation is disproportionately high in minorities with diabetes (ADA, 2011). Diabetes is especially problematic for African American female elders over 55 as they develop greater complications from diabetes (ADA, 2009) and have higher rates of poverty than other races (Cawthorne, 2008).

Although, we do not know how African American family caregivers of persons with dementia have diabetes, this is important to discover due to the amount of time dementia caregiving requires that may interfere with their disease management. Learning how African American caregivers manage the chronic disease of diabetes informs the scientific community about the relationship of time for self-management and the physical health outcomes of self-management behavior in this population. Because the family is so dependent on particular women family member caregivers, determining what are the competing demands of self-management of diabetes given varying levels of caregiving of persons with dementia and how self-management activities are prioritized to maintain health, self-management of diabetes activities, and glycemic control are important

research questions that need to be answered. The purpose of this study is to answer these research questions before a theoretical model of self-management of diabetes for African American family caregivers of persons with dementia can begin to be developed. The identification of self-management of diabetes behaviors and perceived barriers to self-management in African Americans older women will provide data for future development of tailored interventions targeting individual and system barriers in communities, with the aim of improving self-management of diabetes behavior.

Importance of Components of Diabetes Self-Management

Self-Management of Diabetes

Self-management can be described as the patient's management of a chronic illness by making individual decisions and responses to their health condition on a daily basis (Ory, 2008). Self-management is crucial to improvements in chronic care. The Institute of Medicine (IOM, 2003) gave self-management high priority for the United States Health System. Successful management of the chronic disease of diabetes is monitoring the blood sugar and reacting accordingly with diet, medication regimen, a balance of rest and exercise, and checking the feet for skin integrity daily (Clark et al. 1991; Lorig & Holman 2003). In 2007 the Centers for Disease Control and Prevention, State of Aging and Health in America Report also prioritized self-management. Models of chronic illness care are structured for patients who are informed and active self-managers (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Clark, Gong, & Kaciroti 2007). Self-management of chronic illnesses is important to the health of individuals, communities, and the nation due to infection control and health care cost containment (IOM, 2003) and is possible when the patient and the health care provider share

responsibility (Ory 2008; Ory & DeFries 1998). The IOM, (2003) recommended education and support to increase the patients' confidence and skills in managing their illness. Specifically, self-management of diabetes in African American women drives this study. Diabetes self-management requires following a regime of daily behaviors and activities in order to avoid complications from diabetes (ADA, 2011; Toobert, Hampson & Glasgow, 2000).

Glycemic Status

The self-management of diabetes requires daily maintenance of glycemic control. Monitoring glucose levels, exercising, following a prescribed diet and practicing foot care are at the forefront as necessary self-care behaviors for a person diagnosed with diabetes. Diabetes self-care requires patients to understand their symptoms. The American Association of Diabetes Educators (AADE) understands the importance of behaviors in diabetes self-management and teaches diabetes educators to base supportive measures on the AADE-7 Self-Care Behaviors program. This program focuses on problem – solving, healthful coping, and reducing risks (American Association Diabetes Educators, 2008). The self-management of diabetes mellitus (T2DM) requires regular monitoring of blood glucose levels (Department of Veteran Affairs, 2007; ADA, 2011). Skelly et al., (2005), found in a sample of African Americans, Native Americans and Whites (N= 698) only 40 % of the entire group tested their blood sugar daily. African Americans in this study were found to understand neither blood sugar readings, nor how to adapt self-care behavior. Assessing the glucose level of the participants by measuring the glycosylated hemoglobin documented an important aspect of the self-management of their diabetes. Knowledge of their blood glucose status compared with their self-report of

health may help the participants draw factual conclusions from their self-management of diabetes behaviors.

Exercise

Interventions for elderly residents with diabetes should include exercise therapy. There are various options. Castaneda et al., (2002) found that a 16 week exercise resistance training program improved the muscle strength and glycemic control in older adults with diabetes. However, it seems the case that overall, African Americans are less likely to exercise than other populations (Zhao et al., 2008).

Foot Care

Foot care is very important to older adults with diabetes as they can acquire ulcers which can become infected and spread systemically (Brown & Heeley-Creed, 2009). Foot ulcers occur over time when diabetes is poorly controlled, causing nerve damage, poor circulation, and repeated infections on the feet. In addition, the person with diabetes should see the podiatrist on a regular basis. Things to avoid in elders with diabetes include walking barefooted, talc on the feet, toe nails too short, poking sharp objects down the nails, and allowing feet to get too hot or too cold. Supervision and organization of the care of persons with diabetes who have foot ulcers is necessary as they are at high risk for complications. Diabetes wounds present differently than other chronic wounds. If the wounds are not adequately assessed and treated, consequences for the patient can be devastating leading to major amputation or death (Bently & Foster, 2008).

Nutrition

Chelbowy, Hood and LaJoie (2010), found that in African Americans with T2DM (n=38) managing diabetes is time consuming and burdensome. The participants

complained of lack of self-control related to dietary restrictions, especially at holiday and family celebrations. They also found that positive social support was influential in following a diabetes diet. African American women with diabetes stated they believed healthy foods were best for the body while at the same time stated they were too expensive, so they did not eat enough healthy foods. McCleary-Jones (2011) found the diabetes knowledge level and self-efficacy of adult African Americans to be independent predictors for dietary self-care activities.

Smoking

Cigarette smoking is a modifiable risk factor for cardiovascular disease in persons with diabetes (ADA, 2012). Cigarette smoking doubles the risk of cardiovascular disease and mortality among persons with diabetes and attenuates any benefits received from modifying any other risk factors (Fagard, 2009). One in five African American women smokes and has diabetes (Black Women's Health Imperative, 2011). Because smoking is an independent risk factor for diabetes and also increases the risk of heart disease, it is important to teach African American women with diabetes to stop smoking. (Black Women's Health Imperative, 2011).

African Americans and Self-Management of Diabetes

As part of the REACH (2010) survey, African Americans reported fewer A1C, lipid, and kidney tests, fewer feet and eye exams, and less diabetes self-management counseling than other populations (King et al, 2004). Whites monitor their illnesses more than African Americans (Silverman, Musa, Kirsch & Siminoff, 1999). This difference in monitoring their condition could relate to African Americans' priority levels in self-care, perceived physical health, health literacy, and traditional approach to self-management,

assuming group affiliation over individualism. African American women concern themselves with the needs of their families and community before their own needs (Banks-Wallace, 2000).

Barriers and Facilitators to Self-Management

in African American Populations

Facilitators

Facilitators to self-management of diabetes in African Americans include family support, following a daily routine, peer support, and gaining knowledge about diabetes (Chelbowy, Hood, & LaJoie, 2010; Tang, Brown, Funnell & Anderson, 2008; Wen, Shepherd & Parchman, 2004). Adherence to medication management, blood glucose monitoring, diet and physical activity recommendations were followed by African Americans with diabetes when there was positive social support (Chelbowy, Hood & LeJoie 2010; Tang, Brown, Funnell & Anderson 2008).

Barriers

Financial barriers impact the self-management of diabetes for African American women. Low income African American women put other's needs first such as ensuring basic needs of shelter, food, and clothing are available for their families (Samuel-Hodge et al., 2005). African American women in this situation may think of health insurance as a luxury, and rely on folk or over the counter remedies to address their self-care needs. The African American family context and relational variables on diabetes self-care and metabolic control have a relationship with A1C levels, depression, anxiety, diet and physical activity (Fisher, Chesla, Skaff, et al., 2000). Because African American women put the needs of their families first, they may delay buying glucose monitoring supplies

and medications to control their blood glucose. Shopping for nutritious foods, according to their prescribed diet, may not be an option for these women who are struggling with limited incomes and eating what other family members eat, which interferes with proper self-management of diabetes.

The 2008 Bureau of Labor report reflects the nationwide unemployment rate for African Americans was at 11.1%, while the nationwide rate was 6.5%. Liao et al., (2011) found in a survey of 28 communities across 17 states that education and income levels are lower in black communities than whites. Also more African Americans did not have health insurance (Gregg et al., 2001), nor did they see a doctor due to the cost. African American women were more likely to indicate financial problems, pain with glucose testing, and visual disturbances from diabetes as barriers to self-care (Schoenberg & Drungle, 2001).

One study of African American women with diabetes found the women did not fully understand their health insurance coverage, or changes that slowed the payment of their Social Security and Medicare/Medicaid benefits (Cagle, 2002). While these women worked and paid taxes, they felt they were not given adequate counsel about tax deductions and retirement plans while they were employed. When they retired they found their benefits to be much less than they had anticipated; as these households were single income families, it was even more difficult to manage their households and their type 2 diabetes. Because the changes in income were not planned for, it negatively impacted their family finances and caused the women to become more dependent on their adult children. This change caused the elders to perceive loss of position as head of household (Cagle et al., 2002). Working African American women believed they lacked the finances

and time to manage their diabetes. They were aware they should check their glucose daily, but ignored not only that need, but the signs and symptoms of hypoglycemia as work was their first priority in order to take care of their families. Therefore limited income can negatively impact self-care behavior of African American women with diabetes both indirectly and directly as they may not be able to afford medications, glucose testing supplies, and eye examinations.

Social Expectations/Cultural Norms

Already the obligatory social expectations as a spouse, parent, and daughter can produce stressful demands on a woman's physical and emotional state (Thoits, 1995) and these negative effects from social roles may also have the same effects on the day to day self-care of African American women with diabetes (Samuel-Hodge et al., 2005). African American women are challenged when they consider measures of self-care as they struggle with self-identity based on their relationship with others and the welfare of their communities. This perception demonstrates Black feminist thought, which believes in ideas developed by African American women that articulate their perspective on their rights to self-describe, account for experiences of oppression, and acknowledge the uniqueness of each woman's journey (Banks-Wallace, 2000). The struggle these women face is prioritizing between responsibility to self and responsibility to others, and this conflict influences an African American woman's self-management of chronic illness (Samuel-Dodge, Headen & Skelly, 2000). Knight and Sayegh (2009) asked whether traditional values could be modified by typical psychosocial interventions. The investigators recommended examining cultural values more closely to assist caregivers in communicating the beneficial and detrimental effects of their traditional values on the

caregivers' health outcomes. This approach is more respectful to their culture and could have a positive impact on their self-management of chronic illness.

Dementia Caregiving as a Particular Barrier
to Self-Management of Diabetes

African Americans, on average, are two to three times more likely to have cognitive impairment in the 55-64 age group than Whites and three to four times more likely to have cognitive impairment in the 85 and older group. African Americans are at especially high risk for acquiring Alzheimer's disease due to their high risk for developing diabetes and high blood pressure (Alzheimer's Association, 2010). Correspondingly, African American family caregivers comprise a large portion of Americans providing unpaid care of family members with dementia. Family caregivers play an integral role in meeting the needs of individuals with chronic diseases associated with aging. Polvika (2005) emphasizes the sacrifices caregivers make to provide informal long-term care at home, which saves money.

Informal caregivers providing care of persons with dementia at home are increasing rapidly. The expectation in African American families is that aging older adults will be cared for at home by their spouse or adult children (Dilworth-Anderson et al., 2004). Caring for elderly family members while at the same time the caregivers are managing their own diabetes, can be more challenging for African Americans for the following reasons: 1) Forty-one percent of African American caregivers of persons with dementia were more likely than White caregivers to provide assistance with three or more activities of daily living (ADLs) including bathing dressing, grooming, getting out of bed, toileting and managing incontinence (National Alliance for Caregiving/AARP, 2009); 2)

Thirty percent of African American caregivers were more likely to have children or grandchildren under age 18 living in their household (National Alliance for Caregiving/AARP, 2009); 3) African American caregivers were on average older (48 years old) than those in other races and most likely to be single or never married (National Alliance for Caregiving, 2009); and 4) African American caregivers have less formal education and fewer financial resources (Connell & Gibson 1997; Dilworth-Anderson et al., 2002). Adult children caregivers of dependent elderly may be challenged by other commitments in their lives which can limit their ability and time to provide care while at the same time care for themselves.

Competition is likely with the added role of dementia caregiving, while dividing the time allotted for self-management of the caregiver's diabetes, yet no literature on this important caregiving role has been found.

The traditional values that foster strong caregiving networks, may negatively impact caregiver health (Dilworth-Anderson et al., 2005). This potential outcome is related to the strong desire to put self-needs after caring for others in the family. Dilworth-Anderson et al., (2004), explained the cultural socialization and sense of duty to family members of African American caregivers play important roles in the perception of dementia caregiving. The researchers also note minority family caregivers prefer to rely on extended family networks rather than formal services in the caregiving process. Additionally, financial pressures and limited resources are barriers to providing formal services from a nursing home and these factors reinforce the expectation that care will be provided at home in African American families (Dilworth-Anderson et al., 2005). African American family caregivers tend to be adult children, extended relatives, or friends, but

often are adult daughters. African American daughters caring for elderly parents and their own children, and working outside the home, face time constraints concerning their self-management. The 2009 National Alliance for Caregiving American Association Retired Persons (NAC)/(AARP) study reports African American family caregivers (59%) had an annual household income of less than \$50,000. Schultz and Shorewood (2008) suggested further exploration of the contextual aspects of caregiver burden be explored. A contextual aspect of caregiving in African American families is the tradition of caring for their relatives at home.

Caregiving Intensity and Caregiving Performance Difficulty

The time-intensity of dementia caregiving requires varying levels of commitment and stamina from family caregivers. The amount of time and level of care provision required depends upon the amount of cognitive decline and subsequent loss of independence. The intensity and burden increases for family caregivers, who are most often women, many of whom quit their jobs to provide care for persons with dementia (Shriver, 2010). When the additional responsibilities of caregiving for a person with dementia are added to the daily regimen of maintaining glycemic status for women with diabetes, the time for self-management may be limited. The diminished time for self-management may increase complications from diabetes in the African American population (Plassman, Langa, Fisher, Heeringa, Weir et al., 2007).

The time required for dementia caregiving may impact work-related factors for these women. In the National Alliance for Caregiving/AARP survey (2009), women reported missing more hours of work per month due to caregiving for 24 hours, compared to men who provided care for 17 hours. Additionally, women spend more money each

month on health care services for family members than men (\$751 and \$490), respectively. Women reported being the only helper or the main helper with care. The demand for time to care for persons with dementia is especially constraining for women caregivers as they often have to turn down promotions, move from full-time to part-time, or leave work altogether. Work outside the home may interfere with self-management of diabetes

Caregiving can negatively affect the caregiver's attention to self-care practices, which can result in poor health outcomes (Balukonis, D'Erramo, Melkas & Chyun, 2008). African American caregiving grandmothers with diabetes (n=68) were found to have difficulty performing self-management behaviors while caring for grandchildren (Carthron, Johnson, Hubbart, Strickland, & Nance, 2010). Caregiving tasks performed by females over 55 were associated with more negative health outcomes than men (Fredman, Doros, Cauley, Miller, & Hochberg, 2010; Monin, & Schulz, 2009).

Dementia care can go on for years and years. Previous research on African American family caregivers has subjectively measured the impact of caregiving on the caregiver's physical health (Haley et al., 2004; Schultz & Sherwood, 2008). Caregivers neglect their own health (Vitaliano, Zhang, & Scanlan, 2003) while managing the memory and behavior problems exhibited by persons with cognitive impairment thus, their health and well-being may be negatively affected (Christaki & Allison, 2006). The underlying assumption is that the responsibilities of caregiving can lead caregivers to neglect their own health, which may lead to physical distress and illness and decreased well-being (Vitaliano, Zhang, & Scanlan, 2003). Utilizing biological indices to assess the health and self-management of diabetes in African American caregivers would provide objective

information of the caregiver's self-care practices. To date, most of the poor health states have been identified as self-report measures. Adding biological indices will augment the self-report data and provide a more complete picture of the caregiver's self-management of diabetes and resulting health.

Comorbidities of the caregiver may affect their ability to provide the needed care to the care recipient. The number of people with chronic conditions is rapidly increasing. Between 2000 and 2030, the number of Americans with one or more chronic conditions will increase 37 percent, an increase of 46 million people. Approximately 28 percent of Americans have two or more chronic conditions and they are responsible for two-thirds of health care spending. In the Medicare program over two-thirds of the expenditures are for beneficiaries with five or more chronic conditions (Robert Wood Johnson Foundation, 2010). Lu and Wykle (2007) studied the broader side of self-management of arthritis and included the stress of dementia caregiving. With a sample size of (n=99) Caucasians (91%) and African Americans (9%). The researchers found impaired physical function in older adult caregivers with arthritis and found them to demonstrate difficulty assisting care recipients with their ADLs of bathing dressing, grooming and ambulation.

In a study with cancer caregivers, Given and Sherwood (2006), noted elderly caregivers are more likely to have comorbid health conditions and decreased physical ability. Aging caregivers of persons with dementia are bound to have comorbidities also. The added stress of providing this care, which can last for several years, has the potential to significantly diminish the caregiver's quality of life and physical health state over time. The current health care system is not designed to accommodate the healthcare needs of people with chronic conditions. Health policy changes to include caregiver self-

management and family caregiving are imperative!

Spiritual Beliefs and Caregiving Performance Difficulty

In the Bible, the book of Mark chapter 8, verse 30, describes the man called Legion who demonstrated demonic behavior and required restraints. A personal conversation with the African American minister who leads the caregiver support groups at the church in South Holland, Illinois, uncovered cultural beliefs of demonic behavior in one's family as a sign from God looking unfavorably upon the family. Because African American families are deeply rooted in their faith, dementia behaviors are interpreted as demonic behaviors in some African American families. This belief contributes to families being reluctant to admit caring for a loved one with dementia, to not seek respite, and delay treatment for the person with dementia. The filial obligation of African American women caregivers, stigma of dementia behavior and religious beliefs, disparity in health conditions, lower socioeconomic status, cause African American women caregivers of persons with dementia to be at risk for poor health conditions. This risk escalates when the caregiver has diabetes. Their physical health could be negatively impacted unless African American women attend to their self-management.

Summary

Family caregivers play an integral role in meeting the needs of individuals with chronic diseases associated with aging. This care has an estimated cost of \$300 billion dollars annually, which could bankrupt the health care system. If clinicians were more sensitive to aging family caregivers' needs in the self-management of their diabetes while they provide dementia care to aging relatives, the caregivers would be able to sustain their roles as caregivers.

We know the prevalence of diabetes in African Americans and the prevalence for Alzheimer's disease of the dementia type in this population will result in more family caregivers being needed and more perceived barriers to self-management of their diabetes. We currently do not know the number of African American family caregivers of persons with dementia due to their reluctance in recognizing their loved one has dementia and folk beliefs that "chronic confusion has a spiritual cause" (Gerdner et al., 2007, p.362). A church-based descriptive design was utilized to assess the self-management of diabetes in older African American women with diabetes that provide varying levels of time-intensive care to family members with dementia.

Information gleaned from this study has the potential to positively impact the cost of health care, while improving the health of a vulnerable population. Better health outcomes for African American women with diabetes and caregivers providing time-intensive dementia care can lead to the sustainability of our health care system.

Conceptual Framework

The self-management of diabetes for older African American women caregivers of persons with dementia model provides a framework to describe associations between caregiver performance difficulty, time intensity of caregiving and demographics and the self-management of diabetes. The framework also guided the PI to determine any association between caregiver performance difficulty, time intensity of caregiving and demographics with HbA1c. The model was developed from the literature. In this model, the amount of time spent in caregiving (caregiving intensity) and perceptions of the difficulty of caregiving (caregiving performance difficulty) leads or determines the amount and kind of self-management activities performed, which are associated with the

HgA1c levels. The demographic attributes of age, education and length of time with diabetes mellitus also influence self- management activities and ultimately Hg A1c.

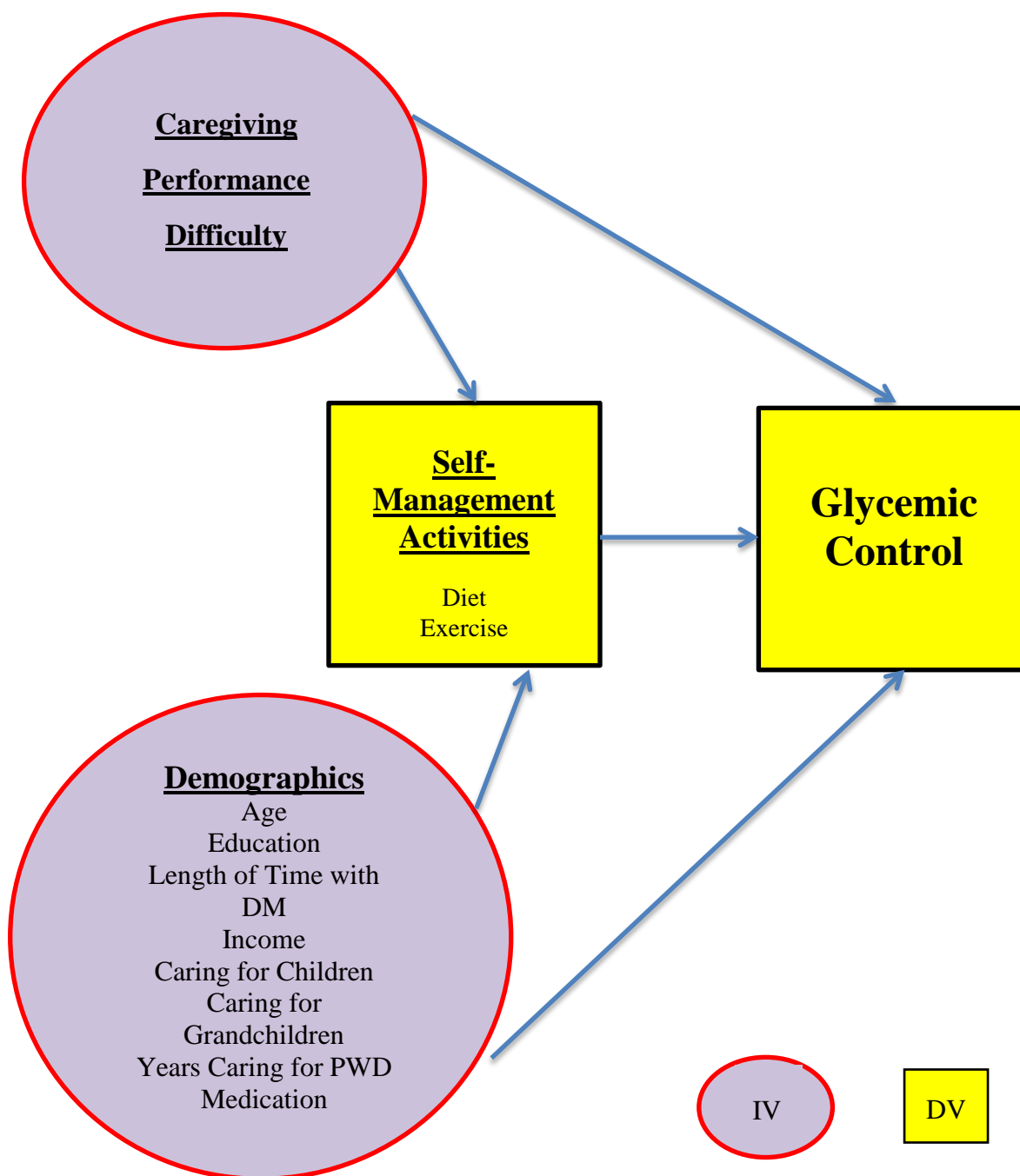


Figure 1. The Self-Management of Diabetes for Older African American Women Caregivers of Persons with Dementia

CHAPTER III

METHODOLOGY

Design

A cross-sectional, descriptive design was used to achieve the study aims. The study population was older African American women with diabetes who also cared for a person with dementia. Measures of demographics as well as caregiving performance difficulty, caregiving intensity, self-management of diabetes, and glycemic control were collected simultaneously in a structured manner.

Recruitment

Networking

Because there are so few studies including the self-management of diabetes in older African American women, the PI made special efforts to obtain an adequate sample for this study. Dr. Gloria Bonner from University of Illinois Chicago introduced the PI to the leader in the church, whom she referred to as “the gatekeeper”, and suggested the gatekeeper would be able to assist with developing trusting relationships, which could facilitate recruitment into the study. The senior pastor wrote a letter welcoming the PI into his church encouraging the research, as he knew how some of the members struggled with caregiving responsibilities and self-care (see Appendix A). An informal relationship began with the gatekeeper as the PI sat with her at church services and was introduced to other members of the congregation. The gatekeeper wrote a letter of support documenting her willingness to introduce the PI to members of the church who volunteer with the caregiver support groups and family caregivers who attend the caregiver Support Forums (see Appendix B).

To promote recruitment efforts, the PI has attended the Covenant United Church of Christ at least once a month for the last year to interact with a leader in the church and meet other members of the church community. The gatekeeper shared information about the caregiver support group meetings she leads at the church and has informed the PI of other resources of caregiver support in the surrounding communities of South Holland. The gatekeeper invited the PI to attend some Caregiver Forums where caregivers of persons with dementia come to seek respite services, information on caregiving, and self-care. She introduced the PI to several leaders of the church and organizers of the caregiver support forums. The gatekeeper expressed interest in the PI's research study as she is a caregiver, is a registered nurse, and saw how facilitating participants for this study would help more members of her church with self-care while caregiving. This person is well respected by her fellow church members and provided the PI with access to the congregation members with caregiving responsibilities. The PI provided an announcement letter to the church's congregation and residents of the surrounding community's members outlining the desire to have African American women over age 50 with type 2 diabetes and who are caregivers of persons with dementia or symptoms of dementia-like behavior to participate in a research study. The purpose of the announcement letter was to identify the population available that fit the inclusion criteria. The church has an alliance with seven other churches who participate in the caregiver forums and the gatekeeper distributed the announcement letter to the members of those churches who participate in the caregiver forums (see Appendix F). A few facts about dementia and diabetes, and how their participation could be helpful to themselves and others were included in the letter. The announcement letter was posted in common areas

of the church, copies were sent to the other seven churches that support the caregiver forums, and the gatekeeper distributed the announcement to church members and participants who attend the “Forums of Caring Together, Living Better” caregiver support groups. As an African American female with caregiving responsibilities for her elderly mother, this researcher began to get trust developed with the potential participants and this facilitated their recruitment in the study.

Recruitment efforts targeted church goers and residents from surrounding suburbs in South Side Chicago who participate in the “Forums of Caring Together, Living Better” caregiver support groups. Gatekeepers organized forums for caregiver support meetings for which the PI distributed an initial recruitment letter asking church members if they would be interested in participating in the study, and saying if they would provide their contact information, the investigator would contact them. The purpose of the recruitment letter was to recruit from the identified qualified population. Additional information on where and when the data was to be collected, what the data consisted of, and what the people would receive in turn for participating was provided in the follow-up letter or phone call. The announcement letter has been an effective method for reaching desired attendance numbers at prior forums of caregiver support, according to the gatekeeper. Additional forums were organized by the gatekeeper in order to introduce the PI to more parishioners to reach the targeted sample size for the proposed study (see Appendix G).

Recruitment for participation in the study became increasingly difficult for several reasons. Some potential participants were younger than age 55 and some of the participants informed the investigator of the stigma of dementia in some families, causing many caregivers to refuse to participate. Additionally, male caregivers with diabetes

accounted for about 20 percent of the attendance at the caregiver support group meetings. Therefore, the IRB was modified three times to include African American women who are age 50, male caregivers were included, and the geography was expanded to central Illinois. Because only one male participated, the decision was made to focus on women with diabetes who care for persons with dementia. Recruitment in the Bloomington-Normal, Champaign-Urbana and Peoria, Illinois cities took place at African American churches in a manner similar to South Side Chicago.

Setting and Sample

Setting

The primary setting of subject recruitment and data collection was at Covenant United Church of Christ in South Holland, Illinois, a village in Cook County. Covenant United Church of Christ has a membership of 2500 African American members. The PI had established a professional rapport with an identified gatekeeper of the Church. Members of the “Forums of Caring Together, Living Better” support groups lead by the Gatekeeper were recruited for the study. The cities of Bloomington/Normal, Champaign/Urbana and Peoria, Illinois were also included in the recruitment and data collection sites. Although several attempts were made, there were no data collected in the Champaign/Urbana area.

The city of South Holland has a large African American population. The census of 2010 reports South Holland as home to 22,000 people with a racial distribution of 74% African Americans, 20% White, 6% Asians, and 5.8% Hispanic or Latino inhabitants. The median income for a household in the village was \$40,000 (U. S. Census, 2010). The congregation is described as low to middle-class, per the gatekeeper.

The city of South Holland is deemed to be the “Most livable Metro-Area suburb of the Chicago metropolitan area (Forbes Magazine, 2007) and has the motto “A community of churches”. More and more African Americans have migrated to this community because of its religious roots. According to the head minister of Covenant United Church of Christ, the history of South Holland’s African American population began with the Great Migration (1910-1970) of African Americans from the southern states to the south suburbs of Chicago.

The Bloomington- Normal community is home to Illinois State University, Illinois Wesleyan University and State Farm Insurance. The total population is 172, 000, while 12,246 are African American. The Champaign-Urbana are has a total population of 203, 276, with 12 percent representing African Americans. And finally the city of Peoria has a population of 112, 936 residents with 27,000 African Americans.

Sample

A purposive sample (n=50) was recruited. Inclusion criteria were: 1) female with diabetes; 2) 50 years of age and older; 3) caregiving for a care recipient who was at least 65 years of age with behaviors consistent with dementia, such as memory loss, wandering, and self-care deficits (Alzheimer’s Association, 2011); and 4); caregiving included assistance with activities of daily living and instrumental activities of daily living for the care recipient at least five days per week at home. The care recipient of 65 years and older ensured them to be considered an older adult with probable comorbidities in addition to dementia. The caregiver could live with the care recipient or come to the care recipient’s home and provide care at least five days per week. There were no exclusion criteria. The rationale for including only women was because African

American women over age 55 have a high prevalence of type 2 diabetes (American Diabetes Association, 2011), most often assume caregiver roles (Schulz & Sherwood, 2008), and have not been included in reported research. Not only are African Americans more likely to develop T2DM, 45 years of age or older, overweight, hypertensive, and have a family history of diabetes, they are also disproportionately prone to a condition called pre-diabetes, where blood glucose levels are higher than normal, but not yet high enough for a diagnosis of diabetes (Centers for Disease Control and Prevention, 2011). Informed consent was obtained from those willing to participate. After enrollment, data collection was scheduled after the caregiver forums or support group meetings. The PI made appointments according to the caregiver's schedule. The PI collected data on the agreed date and time at the respective churches.

Data were collected at the support forums. The following data were collected by the PI: report of diabetes self-management activities including diet, exercise, cigarette smoking, glucose monitoring, and foot care; HbA1c level; caregiving performance difficulty; and report of caregiving intensity measured as time spent in a 24 hour period. The activities of self-management of diabetes were compared to time intensity of caregiving to learn how the variation in time affects activities of self-management.

Self-report questionnaires concerning diabetes self-management activities and dementia caregiving intensity were read to the participants if they chose; they were asked about performance difficulty with caregiving, and glycemic status check was performed.

Informed Consent

A description of all aspects of the study were read by the participant, or read to the participant if necessary. Written consent was obtained from the participant prior to

any data collection. The participant kept a copy of the signed consent form. Consent was voluntary and may have been revoked at any time. The participant was not coerced, manipulated, or pressured to participate in the study. The potential risks to the participant were that they may have exposed that they are not managing their diabetes well. This may have caused some embarrassment. The PI responded to the participant's responses in a non-judgmental manner as the interest was to better understand how they self-manage.

Study Variables

Study variables included dependent and independent variables: the dependent variable self-management of diabetes activities is displayed in Table 1; the dependent variable glycemic status is displayed in Table 2; independent variable caregiving performance difficulty is displayed in Table 3; and the independent variables of participant demographics are displayed in Table 4.

Table 1. Dependent Variable Self-Management of Diabetes Activities

Diet	Exercise	Blood Glucose Testing	Foot Care	Smoking Status
General/ Specific				Smoke/ Non-smoke
Days per week	Days per week	Days per week	Days per week	Cigarettes smoked per day
Total	Total	Total	Total	Total

Table 2. Dependent Variable- Glycemic Status

Variable Name	Measure
Glycemic Status	Glycosolated hemoglobin

Table 3. Caregiving Performance Difficulty

Variable Name	Measure
Caregiving Performance Difficulty	Caregiver Reaction Assessment
Time Intensity of Caregiving	Hours per day caregiving

Table 4. Independent Variables- Participant Demographics

Variable Name	Type	Description	Code
Annual Income	Continuous		0= <30,000 1=>30,001
Education	Continuous		1=some high school 2= high school graduate 3=some college 4= Bachelor's degree 5= Graduate degree
Years with diabetes	Continuous	Years with diabetes	
Age	Continuous	Age in years	
Medications	Continuous	Do you take medications for your diabetes?	Yes= 1, No= 0
Diet only	Categorical	Do you manage your diabetes with diet only?	Yes= 1, No= 0
Glucose testing routine	Continuous	Days per week	
Years caring for a person with dementia	Continuous	Months or years	
Caring for children	Categorical		Yes=1, No=0
Caring for grandchildren	Categorical		Yes=1, No=0
Comorbidities of the caregiver	Continuous	Number of comorbidities besides diabetes	

Dependent Variables

Diabetes Self-Management

Summary of Diabetes Self-Care Activities Survey

The Summary of Diabetes Self-Care Activities Survey (SDSCA) (Toobert & Glasgow, 1994) assesses five aspects of the diabetes self-care regimen: general diet, exercise, cigarette smoking, and blood glucose testing. The instrument is an 11-item questionnaire that assesses levels of self-care behavior over a seven day period. The survey has undergone validity and reliability testing in numerous studies through factor analysis, inter-item correlations, and test-re-test reliability (Toobert & Glasgow, 1994; Toobert, Hampson, & Glasgow, 2000). Toobert, Hampson, & Glasgow, 2000, recommend use of inter-item correlations to measure internal consistency reliability. The tool is well validated with moderate stability measure (0.43 to 0.58) of test-retest was performed during instrument revision. The 11- item scale is a commonly used instrument with good psychometrics. The PI chose to use the revised version of the tool including a subset of the scales based on the PI's idea of what is important to the health outcomes of these women. Using the revised version of the scale also helped limit participant burden.

The tool has been used with African Americans to examine the relationship between complementary alternative medicine and diabetes self-management (Bell et al, 2006) and to study the effect of multigenerational legacies of diabetes on health beliefs and behaviors (Scollan-Koliopoulos, O'Connell, & Walker, 2007). In the Bell study, positive associations were shown with self-management of diabetes behaviors of following diet, self-monitoring glucose, foot inspection, medication adherence and use of complementary alternative medicine ranging from 31% to 91% respectively. The r values

and inter-item correlations were not reported. The criterion validity of the scale in the Scollan-Koliopoulos study was demonstrated by showing the participants' perceptions of controllability of their diabetes was positively related to their self-care behavior in terms of insulin and pill adherence. Inter-item correlations were not reported. The income levels of the participants in this study ranged from below \$20,000 to over \$70,000.

Administration of the tool took approximately 5-10 minutes. The revised SDSCA 11-item scale was also tested by Schmitt et al., (2013) with a N=110 participants. The Chronbach's alpha was 0.63, inter-item correlation of scale items $r=0.47$, retest correlation $r=0.40$, and the mean of criterion-related correlations for general diet, specific diet and exercise was $r=0.23$. For the scales general diet, exercise, blood glucose testing and foot care coefficients between 0.69 and 0.88 were found. The specific diet scale had a low coefficient of 0.15 which is consistent with results by Toobert et al., (2000).

Scoring the SDSCA Instrument

Scores were calculated for each of the five regimen areas assessed by the SDSCA: Diet, Exercise, Blood-Glucose Testing, Foot-Care, and Smoking Status. For items 1-10, use the number of days per week on a scale of 0-7. Next, general diet equals the number of days for items 1 and 2. Specific diet equals mean number of days for items 3 and 4, reversing item 4 (0=7, 1=6, 2=5, 3=4, 4=3, 5=2, 6=1, 7=0). Given the low inter-item correlations for this scale, using the individual items is recommended. Exercise equals the mean number of days for items 5 and 6. Blood glucose testing equals the mean number of days for items 9 and 10. Smoking status equals item 11 (0=non-smoker, 1 = smoker), and number of cigarettes smoked per day. The total of the scores reflected how compliant the

participant was with self-management of diabetes activities. The participants were asked how many days per week they performed each activity. The total scores of each subset of activities were combined and the total score was measured as a continuous variable.

Administration of the tool took approximately 5-10 minutes. An example of scoring the tool might be if the participant has been told to check their blood glucose daily, but they choose to check it one a week, they eat red meat seven days a week, they eat fruit and vegetables 2 days a week, they eat healthy three days a week, exercise one day per week, check their feet three times a week and do not smoke, could have a score of 1.6, meaning the suggested activities of self-management of diabetes were not adhered to on a daily basis in this case.

Glycemic Control

Glycemic status was measured by the Hemoglobin HbA1c (HbA1c). Glycosylated hemoglobin is measured as the ratio of glycosylated to non-glycosylated hemoglobin (Peterson, Pavlovich, et al. 1998). Higher levels of glucose in the blood contribute to more binding and result in higher levels of glycosylated hemoglobin. Glycation occurs over the entire 90-120 day life span of the red blood cell (Kilpatrick, 2000). HbA1c can be interpreted as an average of the blood glucose present over the past 3-4 months and is a useful index of mean blood glucose in the treatment of patients with diabetes (Rohlfing, Little, et al., 2000). HbA1c under 6% is considered normal (Gomero, McDade, Williams & Lindau, 2008). The ADA (2007) recommended treatment goal for the diabetes population is HbA1c of 7% or less although the target could be higher for older adults (Chin, Drum, et al., 2008). The average glucose converts percentage of HbA1c to units of mg/dL or mmol/L so it can be compared to glucose levels from home monitoring systems

(ADA 2007; Nathan et al., 2008). The translation of the HbA1c level to the estimated average blood glucose status allows patients with diabetes to have a better understanding of how well they are managing their diabetes daily and over the prior three months.

The HbA1c is a biological index for diabetes self-management, which can be collected from a fingerstick of 3 drops of blood dropped onto filter paper. Blood spot collection offers a convenient, minimally invasive alternative to venipuncture (Lindau & McDade, 2007; McDade, Williams, Snodgrass, et al. 2007). Blood spots facilitate in-home sample collection, and can be performed by non-medically trained personnel (Williams & McDade, 2008). Accuracy of the HbA1c home test has been determined by comparing physician-collected dried blood spot samples to venipuncture whole blood hemolysate samples. Correlation of the blood spot HbA1c obtained from the doctor's office blood specimen with the sample obtained from the venipuncture specimen was $r=0.978$ (Ray & Kerestan, 2000).

The reliability of the HbA1c test is supported by the National Glycohemoglobin Standardization Program (NGSP) and continues to standardize assay results to generalize them to larger studies and populations (Rohlfing, Little, et al., 2000). The Roche Unimate method used by the National Social Life, health & Aging Project (NSHAP) study is NGSP-certified, confirming the reliability of the measure to determine the participants' glycemic status. The test was used to measure the caregiver's HbA1c to compare it to their self-report measure of self-management of diabetes activities.

The accuracy of the HbA1c test is supported by the assay techniques for HbA1c including affinity chromatography, electrophoresis, high performance liquid chromatography (HPLC), and immunoassays. The "gold standard" of these methods is

assay by HPLC (Halwachs-Baumann, Katzensteiner, et al. 1997; Ray & Kerestan, 2000). For the A1C assay used, high correlation of results is reported when compared to clinical standard methods (Flexsite, Williams, & McDade, 2008). The test has been performed on African Americans to monitor their self-management of diabetes. The HbA1c test kits were obtained from HealthPoint Diagnostics, Inc. located in Lincolnshire, Illinois. The collection procedure took no more than eight minutes. An estimated average glucose scale has been developed to facilitate interpretation of HbA1c level for promoting improved self-management of diabetes.

Independent Variables

Caregiving Performance Difficulty

Caregiving performance difficulty was measured by the Caregiver Reaction Assessment (CRA) tool, a 24-item instrument designed to measure the reactions of family members to caring for elderly relatives with a variety of illnesses (Given et al., 1992). The CRA was chosen to measure caregiving performance difficulty of caring for a person with dementia. The tool has been widely used to measure caregiver burden as it has sound psychometrics and captures specific domains of the reaction to caregiving. The instrument consists of five dimensions (caregiver's esteem, lack of family support, impact on finances, impact on schedule, and impact on health). The self-esteem dimension presents how caregiving makes the caregiver feel, specifically whether it is a privilege to care, they want to provide care, enjoy caring, caring makes them feel good, caring is important to them, caregiver can never do enough to repay care recipient, or caregiver resents having to care. Lack of family support includes difficulty in getting help with caregiving, feeling abandoned, feeling as though family left them alone to provide care,

family working together to provide care, and others dump caregiving responsibility on them. Impact on schedule includes if the caregivers had to stop working in order to provide care; eliminated activities from the schedule to provide care; centered their activities on caregiving; visited family and friends less; and were interrupted throughout the day and night to provide care. Impact on health includes how caregiving impacts physical health, if they feel healthy enough to care, and if they feel tired all the time. Caregiving's impact on finances includes difficulty in paying bills, if finances are adequate, and if caregiving causes a financial strain on the family. Evidence supports the CRA as a good instrument for discovering differences in the reactions in various groups of caregivers over time. The mean inter-item correlations for each of the 5 dimensions were moderate: .47 .56 .54, .51, .60 respectfully. Construct validity of the tool is demonstrated in patient dependencies in activities of daily living and caregiver depression due to their affiliation with burden in conceptual models, used to explain the impact of caring on a family members' schedule and the influence on their health. The scale has a high degree of reliability with ranges of Cronbach's alpha from .82 .90, .85, .80, .81 for each of the five dimensions.

The CRA has been used with African Americans (n=96) to assess their reaction to caregiving (Carr, 2007). Construct validity was demonstrated by the number of subscales being correlated with the level of dependencies in ADL and caregiver depression, because of the way they relate with indicators of burden in conceptual models.

Scoring the CRA

Scoring the CRA requires adding the respondent selections after reversed scored items were coded. To compare subscales of different lengths, item scores for each

subscale were totaled and divided by the number of items in each subscale. Higher scores reflect higher perceived burden (Given and Given, 1992). The analysis was performed with the total caregiving performance difficulty scores. An example using the CRA measure would be if a caregiver provided care twenty-four hours a day, had to stop working to provide care, felt abandoned by other family members, their health got worse while caring, and they agreed that there was a financial strain on the family due to caregiving, the caregiver's total score will be higher suggesting high level of burden or caregiving performance difficulty (Given et al., 1992).

Caregiving Intensity

Caregiving Intensity was measured by asking the caregivers to record their hours of care provision in a 24-hour period. This measure was chosen because the number of hours spent caregiving in a 24 hour period provides information on how much time the caregiver has left for self-management of their diabetes. Based on the information received from the caregivers, hours of caregiving will be recorded. The intensity of dementia caregiving includes living with the client and assisting with activities of daily living (ADLS), instrumental activities of daily living (IADLS), and behavior management with minimal, intermittent, or constant supervision. The higher number of hours spent caregiving will reflect the amount of care and supervision required by the care recipient. The depth of dementia caregiving has been described in the National Alliance for Caregiving/AARP Survey (2009). The time intensity of dementia caregiving data will enhance the meaning of the CRA data and will be measured as a continuous variable. The survey should take no longer than three minutes to complete.

Adherence to Diet and Exercise from the Self-Management Tool

Two items from the SDSCA were used as independent variables in Aim 2 because those participants who used diet only to control their diabetes and those who exercise, in order to determine a relationship with HbA1c. Others measures of self-management activities were not included because foot care, glucose testing, and smoking do not influence HbA1c.

Demographic Characteristics

The participant characteristics collected included age, race, education level, income, marital status, work outside the home, living conditions such as living with spouse or person like a spouse, whether they have children or extended family members living at home, number of years of caregiving, self-reported number of years with diabetes, glucose testing routine and names of diabetes medication. Participants were also asked to report how many other medical conditions they have besides diabetes and the number of other family members they care for.

Procedures

Data Collection

With approval of the Institutional Review Board at the University of Iowa, the PI began data collection to answer the question: “What is the relationship between diabetes self-management activities, caregiving performance difficulty, caregiving intensity, and glycemic status of older African American women with diabetes?” Data were collected at the support forums. The following data were collected by the PI on each participant: report of diabetes self-management activities including diet, exercise, cigarette smoking,

glucose monitoring, and foot care; A1c level; caregiving performance difficulty; and report of caregiving intensity measured as time spent in a 24 hour period. The activities of self-management of diabetes were compared to time intensity of caregiving to learn how the variation in time affects activities of self-management.

Self-report questionnaires concerning diabetes self-management activities, and dementia caregiving intensity were read to the participants if they chose. They were asked about performance difficulty with caregiving and glycemic status was performed. The entire data collection process took approximately one hour per participant. The data were collected after the caregiver forums. Care and sensitivity were shown to participants as breaks were provided between the hour-long forum and the beginning of data collection. Breaks were also provided during data collection, along with healthy snacks and beverages. Appointments were made for data collection to take place at another time at the church for those willing participants who were not able to stay after the forums.

Data Management

The data will be stored for no more than five years in a locked box and kept in a locked drawer in the PI's office. The PI and a research assistant were the only ones with access to the data. The research assistant entered the data into the secured research server data collection site at Illinois State University. The data were used for comparative analysis and the results may be used to develop tailored interventions in the future. Caregiver demographic data will be used in future studies to help answer more questions on the self-management of diabetes in a longitudinal study to potentially lead to testing interventions. Confidentiality was strictly observed at all levels of data handling. Identifiers (subject numbers) were assigned to all participants and used to collate their

data. Completed interviews, surveys, and demographic data are kept in a locked drawer in the PI's office. All responses were reported as group responses.

Personal identifiers were removed and a generic numbering system was used. The PI was the only one to have access to the personal identifiers of the participants, as the research assistant worked from de-identified data. The list of personal identifying information was stored in a locked cabinet in the PI's office. The data will be destroyed by incineration after five years.

Data Analysis

Data were analyzed with statistical analysis software (SAS). Descriptive statistics of the sample were computed using means (SD) for normally distributed, continuous variables. Categorical variables were described with frequency and percent. It is important to note that caring for grandchildren is a binary variable, coded 0-1, income is a binary variable, coded 0-1. The ordinal education variable was treated as a numeric variable, rather than using as a dummy variable. Two dependent variables were analyzed: self-management of diabetes activities and glycemic status. Analysis of these outcomes proceeded in two phases. First, univariable simple linear regressions were used to characterize the associations between each of the independent variables and the dependent variables of interest. Second, multiple linear regression was employed for each of these dependent variables in order to develop descriptive models which adequately address the study aims. Multivariable model selection began in each case by specifying a large model including all of the potential predictor variables, and eliminating apparently unimportant variables via backwards selection with a p-value threshold of 0.20. This approach was chosen in order to strike a balance between model fit and ease of

interpretation. Backwards elimination begins with all independent variables in the model. Next it will find the most non-significant independent variable upon present statistical criteria, in this case ($p > 0.20$) and remove it from the model. It will continue to find the next non-significant independent variable and remove it from the model until all non-significant variables have been removed. Deleted variables do not get back into the model (Kim and Mallory, 2013). The backward selection allows the PI to focus on the independent variables that are associated with the dependent variables of interest HbA1c and self-management of diabetes activities. This process brings to the forefront the specific aspects of self-management of diabetes that may be facilitators or barriers to self-management of diabetes in older African American women caregivers of persons with dementia. The probability threshold was not changed to more stringent values such as 0.05 or 0.10 for the multivariate models because of the exploratory purpose of this study and the PI did not want to potentially lose any variables which may demonstrate a relationship with the dependent variables HbA1c and self-management of diabetes activities. Also to address issues of power, a probability level of .05 or 1.0 with sample size of 50 may have been too conservative.

The data were analyzed using the GENMOD procedure of the SAS statistical analysis software version 9.3. The data were entered into a password protected secured research data site as categorical and continuous data. There were no missing data.

Assumptions

Residual analysis was performed to determine if the model adequately fit the data. There was no evidence that the residuals violated the normality assumption and there was no evidence of heteroscedasticity. Collinearity was not a problem with the multivariable

analysis. Prior to the analysis the PI assumed the HbA1c would serve as the best dependent variable to learn how the participants self-managed their diabetes and provided care to a family member with dementia.

Specific Aims

Aim One: Describe the amount of variation in diabetes self-management activities explained by caregiving performance difficulty, caregiving intensity, and caregiver demographics (age, education, income, years with diabetes, diet only, medication, glucose testing routine, caring for children, caring for grandchildren, number of comorbidities of the caregiver). Univariate analysis was conducted using simple linear regression with diabetes self-management as the dependent variable and caregiving difficulty, caregiving intensity, HbA1c, and subject demographic information as independent variables. A multivariable analysis was also conducted with diabetes self-management as the dependent variable and the same independent variables using multivariable linear regression.

Aim Two: Describe the amount of variation in glycemic control (i.e., HbA1c \leq 7% and $>$ 7%) explained by two diabetes self-management activities (i.e., diet and exercise). Univariate analyses were performed by comparing the means of explanatory variables in the two HbA1c groups. A multivariable analysis was also conducted with HbA1c as the dependent variable using logistic regression to explore relationships between caregiving performance difficulty and demographics with good and poor glycemic status.

Adherence to medications (i.e, antiglycemic oral meds and insulin) plays a major role in glycemic control. Because, data were not collected with regard to medication

adherence, the analysis for aim two was limited to those in the sample who were managed by diet only in order to control for the influence that oral glyceemic meds and/or insulin adherence would have on the findings.

Summary

The data were analyzed to examine the relationship between diabetes self-management activities, caregiving performance difficulty, caregiving intensity, glyceemic status, and subject demographic characteristics. Caring for a person with dementia is time-intensive and diabetes self-management activities require a daily regimen of activities. The demands of dual responsibility on the subjects' time, warranted investigation to assess diabetes self-management behavior in older African American women caregivers of persons with dementia. The findings help to address a gap in the literature on this population and provide evidence for future intervention research.

CHAPTER IV

FINDINGS

Introduction

In this chapter, participants are described and findings are presented by specific aim. The numbers of potential participants who attended caregiver forum meetings reached 584 people. However those who fit the recruitment criteria, (i.e. women age 50 or older with diabetes, who are caregivers of persons with dementia), were less than anticipated. Eighty-one caregiver forum participants were eligible to participate in the study. Approximately 12% of the people attending the caregiver forums participated in the study.

A number of recruitment challenges were encountered, including the time of year (around the Thanksgiving and Christmas holidays), bad weather and reluctance to share personal information concerning caregiving with the PI. A number of potential participants expressed no interest in making appointments, cancelled appointments or were no-shows (see Table 5).

Description of the Sample

The demographic information of the sample can be found in Table 4. Fifty (50) African American women, age 50 and older who served as caregivers to a person with dementia participated in the study. The mean age of the caregivers was sixty-two with a range of (50-76). There was a wide range of variability in the length of time participant's had diabetes from four months to 36 years, with a mean of nine years. Likewise, the length of time participants reported caring for a person with dementia ranged from four months to 12 years, with a mean of three years. On average, participants reported

caregiving to a person with dementia for eleven hours per day with a range of (0.71-20.57).

Most of the sample was comprised of persons of modest means. Over half (54%) percent of the participants' income was under \$30,000. Because initial analyses suggested that the mean income of participants was skewed by outliers, it was dichotomized into participants earning \$0-30,000, and participants earning more than \$30,000 annually. Four percent of the participants did not complete high school, while 36% percent of participants reported graduating from high school, 32% had some college education, while 20% of the sample graduated from college. Thirty-six percent of the participants were caring for grandchildren, while 26% cared for children.

The most frequent comorbidities of participants were hypertension, hypercholesterolemia, and respiratory conditions. The average number of participant comorbidities was 3 with a range of (1-12). The majority of participants (64%) reported taking medications for their diabetes (see Table 6).

Table 5. Recruitment and Data Collection Observation Sites (N-50)

Church	Location	Caregiving Forum attendants	Caregivers interested/ Did not complete	Caregiver participants
Covenant United Church of Christ	South Holland, IL	425	67	38
Mt. Piscah Baptist Church	Bloomington, IL	14	5	5
Ward Chapel	Peoria, IL	75	4	2
St Paul Christian Church	Peoria, IL	70	5	5
Totals	5 sites	584	81	50

Table 6. Caregiver Demographics and Comorbidities of the Sample (N=50)

Continuous Variables	Mean (SD)	Range	Median
Age (years)	62.22 (7.6)	50-76	61
Duration of diabetes (years)	9.01 (9.1)	0.25-36	5.00
Duration of caregiving (years)	2.94 (2.9)	0.33-12	2.00
Number of comorbid conditions	2.94 (1.0)	1.00-12.00	3.00
Caregiving intensity (hours per day)	10.79 (7.7)	0.71-20.57	10.28
Categorical Variables	Frequency (%)		
Education			
Some high school	2 (4%)		
High school graduate	18 (36%)		
<4 years college	16 (32%)		
Bachelor's degree	10 (20%)		
Meds only	32 (64%)		
Diet only	18 (36%)		
Current Smoker	6 (12%)		
Caregiver for children	13 (26%)		
Caring for grandchildren	18 (36%)		
Income < \$30,000	27 (54%)		
Comorbid condition	3.08 (1.26)		
Hypertension	30 (60%)		
High Cholesterol	13 (26%)		
Respiratory	12 (24%)		
Gastrointestinal	10 (20%)		
Pain	6 (12%)		
Endocrine	4 (8%)		
Sensory	4 (8%)		
Mobility	4 (8%)		
Mental Illness	3 (6%)		
Cancer	2 (4%)		

Caregiving Burden Reported by Participants

Caregiving Performance Difficulty

According to the first subscale of the Caregiver Reaction Assessment, which estimates the impact caregiving has on the caregiver's schedule, most participants agreed that they had to stop working in order to provide care, eliminated activities from the schedule to provide care, centered their activities on caregiving, visited family and friends less and were interrupted throughout the day and night to provide care. The second subscale, in which caregiver's esteem is assessed, demonstrated that, on average, participants moderately agreed that they enjoyed caring. In the third subscale, which assesses family support reflected that, on average, caregivers reported that they had a low level of family support. In the fourth subscale, in which the impact of caregiving on caregiver health is assessed, about half of the participants reported a moderate impact on their health as a result of caring for a person with dementia. And finally, in the fifth subscale assessing the impact of caregiving on caregiver finances, most participants agreed that caregiving put a strain on the family finances (see Table 7).

Table 7. Participants' Reported Caregiving Performance Difficulty (N=50)

Caregiving Performance Difficulty	Mean (SD)	Range	Median
Impact on schedule	3.16 (1.00)	1.00-5.00	3.00
Self-esteem	4.30 (0.60)	2.28-5.00	4.42
Lack family support	2.80 (1.09)	1.00-5.00	2.60
Impact health	2.59 (0.72)	1.00-4.25	2.75
Impact finances	2.49 (1.32)	1.00-5.00	2.33
Total Caregiving Performance Difficulty	3.07 (0.55)	2.99-4.60	2.99

Time Intensity of Caregiving

On average, participants reported spending 11 hours per day caregiving for a person with dementia.

Self-Management and Glycemic Control in the Sample

The dependent variables are self-management of diabetes activities and glycemic status (HbA1c). On average, participants checked their blood glucose three days a week. However, 32% of the participants marked they did not check their blood glucose at all in the past seven days. On average, participants reported managing their diabetes by following a general diet three days per week, and exercising two days per week; those participants who reported following a specific diet ranged from seven to two days with an average of four days. On average, foot care was performed by participants three out of seven days. Six people smoked; of those who smoked, most reported smoking less than one cigarette per day (see Table 8).

Table 8. Participants' Self-Management of Diabetes and Glycemic Status (N=50)

Variable	Mean (SD)	Range	Median
Glucose Test	3.21 (2.94)	0.00-7.00	2.50
General Diet	4.49 (1.92)	0.00- 7.00	5.00
Specific Diet	4.43 (1.16)	1.50-7.00	4.50
Exercise	1.84 (2.21)	0.00-7.00	1.00
Foot Care	3.38 (2.29)	0.00-7.00	3.50
# Cigs/Day	7.47 (1.56)	0.00-10.00	0.00
HbA1c total	7%	4%-12%	8%

According to the American Diabetes Association (ADA), the HbA1c for those with diabetes should be 7.0% or less (2012). The HbA1cs ranged from 4.40 to 11.70 with a mean of 7.47. See Table 6 for characteristics of the study's two dependent variables.

Aim One

Aim One: Describe the amount of variation in diabetes self-management activities explained by caregiving performance difficulty, caregiving intensity, and caregiver demographics (i.e., age, education, income, years with diabetes, years caring for a person with dementia, caring for children, caring for grandchildren, number of co-morbidities of the caregiver and medications).

For Aim One, self-management of diabetes activities was used as the dependent variable. The self-management of diabetes activities includes the individual items of eating the prescribed diet, exercising, checking the feet and shoes, checking blood sugar and smoking.

Backwards stepwise regression with a p-value threshold of 0.2 was used to select variable for subsequent regression analysis. The association between independent variables explored for their potential association with the SDSCA summary score are found in Table 9.

After backwards selection, medication indicator, age, education and caring for grandchildren remained in the model. Medication use was associated with an SDSCA value which was 5.02 units higher on average than diet alone indicating that, for those who state they take one or more medications to manage their diabetes, they also report higher scores for other dimensions of self-care assessed with the SDSCA measure. Each additional year in age was associated with a score on the SDSCA 0.22 units higher on

average, indicating better self-management of diabetes behavior with increased age. Participant levels of education are displayed in table 10. Education was analyzed as an ordered factor, or a continuous variable, rather than an unordered factor (or nominal) factor. Each additional year of education was associated with 0.99 units higher on average. Caring for grandchildren was also associated with a self-management score which was higher on average by 2.41. Therefore, older age, caring for grandchildren, and more years of education also are associated with better self-management of diabetes, demonstrating 37% of the variability in SDSCA (see Table 10).

Table 9. Aim One Univariable Analyses Summary Diabetes Self Care Activities (N=50)

Variable	Parameter Estimate	Standard Error	P-value
Medication Indicator	1.0816	0.2902	0.0005
Income < 30k	-0.1844	0.3162	0.563
Age	0.03414	0.02044	0.101
Education	0.09295	0.15773	0.558
Years with Diabetes	0.02476	0.01718	0.156
Years of Caregiving	-0.03218	0.05498	0.561
Caring for Children	0.04054	0.36056	0.911
Caring Grandchildren	0.8108	0.308	0.0114
Comorbidities of the Caregiver	0.2101	0.1232	0.0947
Caregiver Performance Difficulty	-0.2703	0.2864	0.35
Caregiving Intensity	0.01645	0.02069	0.431

Table 10. Aim One Self-Management of Diabetes Activities Final Model (N=50)

Variable	Parameter Estimate	Standard Error	P-Value
Intercept	-3.57	6.56	0.59
Medication Indicator	5.02	1.46	0.00
Age	0.22	0.09	0.02
Education	0.99	0.71	0.17
Caring Grandchildren	2.41	1.49	0.11

R-Squared 0.3706

Aim Two

Aim Two: Describe the amount of variation in glycemic control (i.e., HbA1c \leq 7% and $>$ 7%) explained by two diabetes self-management activities (i.e., diet and exercise).

An analysis of two diabetes self-management activities (i.e. diet and exercise) was performed to determine an association with participant's HbA1c. Because medication adherence was not measured as a part of the SDSCA tool (rather participants were simply asked if they were on medications as part of the demographic survey), participants who managed their diabetes with diet only were used to determine an association with HbA1c and self-care. Eighteen participants stated that they used diet only.

For clinical relevance, two descriptive categories for glycemic status Good Control (HbA1c \leq 7) and Poor Control (HbA1c $>$ 7) were created. T-tests were performed for differences in means between the two HbA1c groups with respect to the

continuous variables, while Chi Squared tests of independence are used for the binary variables.

There were no statistically significant differences between those with good and poor glycemic control among the variables explored in the 18 participants who reported managing their diabetes with diet and/or exercise alone (see Table 11).

Dementia Caregiving, Time Intensity and Demographics

on HbA1c

Based on the lack of statistically significant differences in diabetes self-management activities between those with good and poor glycemic control, a decision was made to continue analyses by exploring the direct association between caregiving performance difficulty, caregiving intensity, and caregiver demographics (i.e., age, education, income, years with diabetes, years caring for a person with dementia, caring for children, caring for grandchildren, number of co-morbidities of the caregiver and medications) and glycemic control using logistic regression on the previously discussed binary HbA1c outcome. This was accomplished using the entire sample (n=50) as the previous limitations in medication adherence variables no longer applied. See Tables 12 and 13 for differences in caregiving performance difficulty, caregiving intensity, and caregiver demographics (i.e., age, education, income, years with diabetes, years caring for a person with dementia, caring for children, caring for grandchildren, number of co-morbidities of the caregiver and medications) among those with good and poor glycemic control. The analysis was performed to determine how much statistical evidence there is to determine a true difference. The data is not surprising assuming there is no difference in the groups (Table 12).

Bivariate comparisons of good control versus poor control of glycemic status with binary variables were analyzed. Dummy variable coding was used for the categorical variables Income, caring for grandchildren, and medication use. The corresponding hypothesis tests are for a difference of proportions between the two HbA1c groups. "Caring for grandchildren is a binary variable, coded 0-1, income is a binary variable coded 0-1. The analysis was performed to determine how much statistical evidence there is to determine a true difference. The data is not surprising assuming there is no difference in the groups (see Table 13).

Eleven caregivers with income under \$30,000 were in good glycemic control, where- as thirteen caregivers in the same income category were not in good control. Thirteen caregivers making over \$30,000 annually¹³ were in good control and 13 were not. Caring for grandchildren, seven caregivers were in good control, while 18 were not. Caregivers not caring for grandchildren, eleven were in good control, while 19 were in poor control. Caring for children, six were in good control, while 18 were not. Medication use was associated with 12 caregivers having good control while 12 were not in control. Those caregivers who did not take medication, 20 were in good control, while six were not in good control.

Dementia caregiving, time intensity and demographics were analyzed with logistic regression. The variables remaining in the final model for HbA1c after backwards selection are age, years with diabetes, years caring, comorbidities, and caregiver performance difficulty. The outcome variables for logistic regression were equal to 1 for participants who had well-controlled HbA1c with 0 for participants who were not well- controlled. Therefore, positive parameter estimates are associated with

better odds of having well controlled HbA1c. Negative parameter estimates are associated with better odds of having poorly- controlled HbA1c.

Each additional year in age was associated with an increase of 0.12 in the odds of a participant having good glycemic control. Experience with caregiving, where each additional year of caregiving associated with an increase of 17.5% in the odds of having a HbA1c less than or equal to seven. Each additional score of caregiving performance difficulty was associated with a 5.1 fold increase in the odds of having a HbA1c less than or equal to seven. This is a result of the multivariate analysis below.

In contrast, variables included in the model that were associated with a decreased likelihood of having good control included comorbidities, where each additional condition was associated with a decrease of 46% in the odds of a participant having a well- controlled HbA1c, and time since diagnosis with diabetes, where each additional year with diabetes was associated with a 7.4% decrease in the odds of having good glycemic control (see Table 14).

Table 11. Bivariate Comparisons in Self-Management Behaviors between those with Good Control vs Poor Control Glycemic Status (N=18)

Variable Name	Mean (SD) <=7	Mean (SD) >7	p-value
Glucose Testing	2.17(3.19)	3.77(3.20)	0.08
General Diet	4.75(1.91)	4.25(1.95)	0.36
Specific Diet	4.38(1.55)	4.48(1.69)	0.82
Exercise	1.83(2.33)	1.85(2.15)	0.98

Table 12. Bivariate Comparisons Good Control vs Poor Control Glycemic Status (N=50)

Variable	Mean (SD) <=7	Range <=7	Median <=7	Mean (SD) >7	Range >7	Median >7	P-value
Age	63.71 (8.35)	50-76	64	60.85 (6.70)	52-76	59.5	0.19
Education	2.98 (1.04)	1-5	3	3.04 (0.99)	1-5	3	0.57
Yrs. diabetes	7.40 (8.97)	0.25-36	4	10.5 (9.14)	0.5-30	10	0.23
Glucose testing	2.27 (3.20)	0-7	0	3.87 (3.20)	0-7	0	0.08
General diet	4.75 (1.91)	0-7	5	4.25 (1.95)	0-7	5	0.36
Specific diet	4.48 (1.55)	1.5-6.5	5	4.48 (1.70)	2-7	5	0.82
Exercise	1.83 (2.33)	0-7	0.5	1.85 (2.15)	0-7	1	0.99
Foot care	3.21 (2.55)	0-7	3.5	3.54 (2.06)	0-7	3.5	0.62
Number comorbidities	0.46 (1.72)	0-8	0	1 (2.60)	0-10	0	0.39
Finances	2.99 (1.30)	1-5	2.66	2.13 (1.25)	1-5	2	0.04
Health	2.57 (0.60)	1.5-4.2	2.63	2.62 (0.83)	1-4.5	2.75	0.84
Support	2.96 (1.23)	1-5	2.8	2.77 (0.96)	1-4.2	2.4	0.36
Esteem	4.26 (0.67)	2.29-1	4.42	4.41 (0.53)	3.29-5	4.43	0.38
Yrs. caregiving	3.20 (2.98)	0.331-10	2	2.72 (2.85)	0.5-12	2	0.58
Caregiving performance difficulty	3.20 (0.60)	2.23-2.26	3.16	2.97 (0.48)	2.26-3.97	2.91	0.13
Caregiving intensity	9.83 (7.38)	0.86-20.68	8	11.68 (7.97)	0.71-20.57	14.86	0.40

Table 13. Bivariate Comparisons Good Control vs Poor Control Glycemic Status- Binary Variables (N=50)

Variable Name	Good Control	Poor Control	P-value
Income < 30k	11(46%)	13(54%)	0.99
Income > 30k	13(50%)	13(50%)	
Caring Grandchildren	7(28%)	18(72%)	0.5
Not Caring Grandchildren	11(37%)	19(63%)	
Caring Children	6(25%)	18(75%)	1
Not Caring Children	7(27%)	19(73%)	
Taking Medication	12(50%)	12(50%)	0.09
Not Taking Medication	20(77%)	6(23%)	

Table 14. Dementia Caregiving, Time Intensity and Demographics on HbA1c (N=50)

Variable	Parameter Estimates	Standard error	P-value
Intercept	-10.2928	4.244563	0.015311
Age	0.116347	0.051435	0.023697
Years with Diabetes	-0.07612	0.03895	0.050658
Years caring	0.161473	0.120787	0.181274
Comorbidities	-0.61972	0.323681	0.055544
Caregiving Performance Difficulty	1.62068	0.685857	0.017747

Summary

The study described how older African American women caring for persons with dementia self-manage their diabetes. Their reaction to caregiving was explored, as well as their routine performance of diabetes management activities such as following a prescribed diet, medication regime, exercising, checking their feet, and monitoring their blood glucose. Time intensity of caregiving for a person with dementia and the influence of comorbidities and demographics in the caregiver were examined. Evidence was found for medication use, age, years of education and caring for grandchildren was related to SDSCA levels. Variables associated with HbA1c were age, years with diabetes, years of caring for a person with dementia, comorbidities and the total score of caregiving performance difficulty. The clinical significance of the analyses are: 1) Increasing age is associated with increasing odds of well controlled HbA1c; 2) Additional years with diabetes are associated with decreasing odds of well-controlled HbA1c; 3) Additional years of caregiving are associated with increasing odds of well-controlled HbA1c; 4) Additional comorbidities are associated with decreasing odds of well-controlled HbA1c, almost a factor of two; and 5) Additional caregiver performance difficulty is associated with very strongly increased odds of having a well-controlled HbA1c.

The data indicates that multiple factors have an influence on these older women caregiver's ability to manage their diabetes. As previously mentioned, many African American households are intergenerational and therefore grandmothers are caring for grandchildren. On top of this responsibility the grandmothers are also caring for a family member with dementia. The research findings of improved self-management of diabetes in caregiving grandmothers may suggest increased motivation to be compliant with self-

management of diabetes activities on a daily basis, in order to raise their grandchildren. The average age of the caregivers was 62 and they had at least three comorbidities in addition to diabetes. The findings suggest increased difficulty with maintaining optimal glycemic control with the competing demands of aging in general and dealing with multiple comorbidities. Increased education levels on average showed an association with improved self-management of diabetes. Medication use also was associated with improved SDSCA. Those participants taking medications, on average may have worse cases of diabetes. In relationship to HbA1c, increased years with diabetes and additional comorbidities showed an association with poor glycemic control, where age additional years of caring for a person with dementia and caregiving performance difficulty were associated with optimal glycemic control.

CHAPTER V

DISCUSSION

Introduction

This study uses a descriptive cross-sectional design with quantitative methods to describe how older African American women with diabetes who care for persons with dementia self-manage their diabetes and at the same time provide time intensive dementia care to a family member. Variables associated with self-care management activities and caregiving intensity, caregiving difficulties and demographics and glycemic status were explored. Chapter V discusses the findings presented in Chapter IV, outlines limitations of the study, addresses implications of the research, discusses practice, education, and policy implications of the research and suggestions based in context with previous literature, my professional and personal experiences.

Summary of Findings

Age, medications, caring for grandchildren, and education, were the independent variables significantly associated with self- management of diabetes with multivariable analysis. Variables demonstrating an association with SDSCA of less significance but needing acknowledgement due to their univariable association with SDSCA are years with diabetes and caregiver comorbidities. Medications, age, additional years caring for a person with dementia, and caregiver performance difficulty were the variables demonstrating those participants with optimal glycemic control. Additional years with diabetes and additional comorbidities were the variables associated with participants in poor glycemic control. This suggests that several variables may have potential for the development and testing of interventions.

Background and Demographic Characteristics

The demographics of the women in the study are quite diverse. The caregivers with diabetes range in age from 50 to 76. Although the distribution of age in this study is similar to findings in the Carthron et al. (2010) study of African American caregiving grandmothers with diabetes who ranged in age from 55-75 years of age, (Mean age- 59.21 years, SD+ 5.22), very different results concerning self-management of diabetes emerged from the current study with caregiving grandmothers with diabetes. In the Carthron et al. (2010) study, the grandmothers caring for their grandchildren were not also caring for a family member with dementia. These grandmothers were found to have a difficult time managing their diabetes due to their caregiving responsibilities. In contrast, in the current study the caregiving grandmothers have the additional responsibility of providing care to a family member with dementia, and were found to have good self-management of diabetes behaviors. This finding may be related to increased motivation to take care of themselves in order to raise their grandchildren.

National statistics demonstrate that on average African American caregivers have less formal education and fewer financial resources. According to the Bureau of Labor Statistics (2012) 80% of Blacks have a high school education, 19% have Bachelor's degrees, and 19% have Master's degrees. Those statistics are in alignment with this study as 20% of the sample had a college education, 32% had less than four years college education and 36 % with a high school education, so this sample was fairly well educated. According to the National Alliance for Caregiving American Association Retired Persons (NAC)/(AARP) (2009), study African American family caregivers (59%) have an annual household income of less than \$50, 000. Compared to the AARP study

with a sample (N=206), most of the participants in this study with a sample (N= 50), earned less than \$30,000 annually, with only ten participants making more than \$50, 000 annually. However, the results of the current study are representative of the national statistics on income for African American women which report the national average median income for African American women is \$30,000 compared to White women at \$37,000 (Bureau of Labor Statistics, 2012).

Diabetes Self-Management

The study participants have diabetes of various durations; ranging from less than a year to 36 years. Each participant controlled their diabetes either with diet only or with medication. Compared to those participants who control their diabetes with diet only, those who take medications are better with self-management activities of eating the right kind of foods, exercising, checking their feet and shoes, and monitoring their blood sugar daily. In this study participants had progressively better HbA1c levels with medication use. There are many possible reasons for this finding. Those women who manage with diet only could be in denial about having diabetes or may not understand the significance of diabetes and their food intake, or not have access to care, or be too focused on caregiving to think about the seriousness of the diabetes, or diet alone may not be enough to manage the diabetes appropriately. It is also possible they don't understand how to follow the recommended diet or may not be able to afford the suggested foods to help them manage their diabetes. According to McCleary-Jones (2010), African American women with diabetes state they know what the best food choices should be, while at the same time state they are too expensive, so they do not eat enough healthy foods. Those

participants who take medications may have a more complicated case of diabetes, and are more deliberate with their self-management activities.

Glucose testing routine was based on how many days out of seven the testing was completed. The mean of the group was found to be three days out of seven. This may be explained by the women who test their glucose levels more often in a seven day period may have a more serious case of diabetes which requires more frequent monitoring. Twenty percent of the participants in the study took medications and checked their blood glucose daily to four times per day. Possibly, the participants who checked glucose daily were more committed to self-management. Skelly et al. (2005) found in a sample of African Americans, Native American and Whites (N=698) that only 40% of the group checked their blood sugar daily. The African Americans in the Skelly study did not understand the importance of the readings or how to adapt self-care behavior. Contrary to the Skelly et al. (2005) study, the participants in the current study generally took monitoring their blood glucose more seriously although, they were not asked what their provider suggested for monitoring, but instead were asked how many days a week they followed instructions.

Foot Care

We know African Americans have to take care of their feet more because their diabetes is worse leading to more circulation problems and more neuropathy (ADA, 2009). The majority of the participants in this study were not checking their feet daily, and they verbalized they did not know they were to check the inside of their shoes for pebbles or damage to the inner soles on a daily basis, as Brown and Heeley-Creed (2009) suggested. Brown and Heeley-Creed (2009) studied older adults with diabetes and

stressed the importance of prevention of diabetic wounds which could lead to devastating amputation or death. These findings support necessary implications for health education to older African American women caregivers with diabetes.

Exercise

Exercise was analyzed to determine an association with HbA1c. Of the twenty-eight participants who exercised approximately 50% had a glycemic status under the recommended 7.0, while the other half had a glycemic status above 7.0. Zhao et al. (2008) found African Americans were less likely to exercise than other populations. Exercise is deleted from the model in this study as there was no association with the outcome variable HbA1c.

Participant's HbA1c

The HbA1c values for the participants were near recommended levels for older persons. A comparison of all demographics found no differences in the groups with good and poor glycemic control. It was interesting to find that increased levels of caregiver performance difficulty increased the odds of having good glycemic control by five times. An explanation of this could be the motivation to manage their diabetes well, in order to remain their caregiver role. Likewise, each additional year caregiving and increased age increased the odds of having glycemic status equal to or less than seven. The PI expected the opposite result due to caregiving responsibilities associated with those with dementia. On the other hand, additional comorbidities severely reduced the odds of caregivers having a glycemic status equal to or under seven by 46%, and the longer a caregiver had diabetes reduced their odds of having good glycemic control. Aging caregivers with

comorbidities, in addition to diabetes, may face more difficulty maintaining good glycemic control due to the length of time caring for a person with dementia can last.

Caregiving Grandmothers

Interestingly, in the current study the caregiving grandmothers who also cared for family members with dementia, had higher HbA1c levels, yet are better managers of their diabetes than those not caring for grandchildren, as measured through multivariable analysis, differing from other study findings (Carthron,2010). Another study by Smithgall (2012) examined grandmothers caring for their grandchildren while managing comorbidities, including diabetes. The findings included 33% of them reporting depression and many of them dealing with three or more comorbidities. One possible explanation for the caregiving grandmothers demonstrating better self-management of diabetes behavior in the current study is the motivation to take their self-management behavior more seriously enabling them to be able to raise their grandchildren. Another possibility may be the grandchildren help with caregiving; however the ages of the grandchildren were not collected. Exceeding the national findings that twenty-four percent of African American grandparents provide care to their grandchildren, twenty-six percent of the participants in this study were caring for children and 36% are caring for grandchildren.

Caregiving

Years caring for a person with dementia ranged from 3 months to 12 years. This is consistent with the literature as McEwen (2000) explains how dementia care can go on for years and years, leading to allostatic load or wear and tear on the physical health of the caregiver (Schultz & Sherwood, 2008). Caring for a person with dementia is time

intensive, meaning the caregiving can be a 24/7 responsibility for one caregiver. The fatigue, isolation and need for constant vigil, can lead to the caregiver neglecting their own health. Comorbidities of the caregiver were collected on the demographic scale, and were analyzed into a univariable model reflecting their association with glycemic status and self-management of diabetes activities. The results demonstrated as the caregiver comorbidities increased the average HbA1c increases. As the caregivers had on average three comorbidities in addition to diabetes to manage, finding time to manage all their comorbidities and care for their family member with dementia may cause them to have more difficulty controlling their glycemic status. The study also showed that as the caregiver comorbidities increased the caregivers level of self-management of diabetes activities increased. This finding may be related to the caregiver making their self-management of diabetes more of a priority, because of the additional chronic illnesses. The study findings suggest the demands of self-management of diabetes, time intensive caregiving for a person with dementia, and managing their own as well as the care recipient's comorbidities, negatively impact the health of older African American women with diabetes.

Hours Spent Caregiving

Time spent caregiving did not demonstrate an association with self-management of diabetes or HbA1c in this study. It was important to learn if a relationship existed between hours of caregiving and self-management of diabetes activities and HbA1c due to the demand of time required for care to persons with dementia. However, the range of caregiving intensity for the caregivers who provided a combined 2075 hours per week of caring for a person with dementia was ranged from 0.86-20.68 with a mean of 9.83 for

those in good glycemic control. The range of caregiving intensity for those in poor glycemic control was 0.71- 20.57 with a mean of 11.68. This finding may suggest those caregivers with higher caregiving intensity find managing their glycemic status more challenging. The results could also mean that those participants on medications have a more serious case of diabetes. The average number of hours per day spent caregiving was eleven. The average hours caregiving in a 24 hour period are added for each day and reported as hours per week spent caregiving. The Shriver Report (2010) on Alzheimer's care reported that 50% of women caring for a person with Alzheimer's disease provides more than 40 hours a week of care. The results of the study demonstrate similar and more serious findings than in the Shriver report, as the caregivers are providing an average of 76 hours per week of caregiving. While the hours per day of caregiving do not show a significant relationship to the dependent variables self-management of diabetes or HbA1c, it may be explained by the smaller sample size (N=50) or that they have adapted their lifestyles to accommodate self-management of diabetes behaviors, and provide care to their family member with dementia.

Limitations of the Study

There are several limitations in the study. First, the sample size is less than the original power analysis called for. The original sample size target was 73 participants at 0.80 power, effect size 0.08 and a p-value of 0.05. This study had a sample size of 50 with a 0.80 power, effect size 0.01 and a p-value threshold of 0.20. Reasons for the smaller sample size include, the season of data collection was right before the Thanksgiving holiday and Christmas, so people were busy and perhaps less interested in participating, until early spring. This time of year was chosen for data collection due to

several caregiver support groups scheduled at the church in South Holland in the fall. The gatekeeper and leaders of the support groups identified this time of year as when the caregiver's require extra support, and the PI was encouraged to attend the group meetings, share my caregiving experiences with family, and recruit participants for my study. The attendance at the meetings was lower than anticipated, therefore recruitment was challenging.

Recruitment took place at the caregiver forum meetings, so the people in attendance already had an interest in gaining caregiver support on some level, therefore the sample was biased. One hypothesis determined from the study is that recruitment should have occurred at other venues to capture the caregivers of this vulnerable population who are not disclosing their caregiver identities and responsibilities, but could benefit from caregiver support. Those persons who were not recruited for this study are even more vulnerable. The participants in the study do fit with national/regional demographics of being better educated, and had lower incomes, most of the participants earned less than \$30,000.00 annually.

A second limitation is the psychometrics of the CRA measure had been tested to assess the caregivers' reaction to caregiving over time. This study was a cross-sectional study. Perhaps the results could have been more reflective of the caregiver's reaction to caregiving if repeated measures were conducted over time. Also, the caregiver performance difficulty summary score was used in the analysis to determine a relationship with the dependent variables. This can be considered a limitation because a previous analysis using backward elimination examined the subsets of the CRA measure and found significance with the impact on finances having a significant relationship with

SDSCA and HbA1c. Therefore, the findings of significance with policy implications (impact on finances due to caring for a person with dementia, while trying to self-manage their diabetes) are diminished. In future studies, a larger sample size will add more power and potentially retain more of the variables in the models associated with caring for a person with dementia and self-management of diabetes activities. Another hypothesis determined from the study is the larger sample size could reveal additional variables that are important in predicting caregiver self-management of their diabetes and their HbA1c.

Another limitation was the decision to use the revised edition of the SDSCA (Toobert, Hampson, & Glasgow, 2000) which did not assess adherence to medical regime therefore limiting the possibility of examining the relationship of the SDSCA to HA1c. The PI chose to use the revised version of the tool including a subset of the scales based on the PI's idea of what is important to the health outcomes of these women. Using the revised version of the scale also helped limit participant burden. The tool is well validated with moderate stability measure (0.43 to 0.58) of test-retest was performed during instrument revision. The 11- item scale is a commonly used instrument with good psychometrics (Toobert, Hampson, & Glasgow, 2000). Future studies will utilize either the full Summary of Diabetes Self- Care Activities Scale or another validated tool to measure participants' adherence to prescribed regimen. One hypothesis determined from the study is that the relationships between caregiver performance difficulty and demographic topics of caring for grandchildren, years with diabetes and age with self-management of diabetes could be better explained with a tool capturing more details of the participant's self-management behaviors.

Implications for Research

There are several implications for the application of the results from this dissertation study.

Recruitment

An important implication is to study and implement recruitment approaches that are culturally and personally sensitive. Approaches to recruitment for a larger sample size of this population in addition to networking and building trust, are to begin discussion about the chronic illness management before discussing the caregiving experience. This approach was effective at the latter part of the data collection, as trust was established and there was a sisterhood of purposeful participation in the name of health promotion for African American women. Dilworth-Anderson et al, (2005) found African American caregivers tend to put the health needs of their family members, before their own. The family dynamics witnessed by the PI in the dissertation study are consistent with Dilworth-Anderson et al. (2005) therefore additional studies need to be conducted to better capture self-management decision-making behaviors in minority populations in the context of family needs and concerns, which can result in effective intervention research.

Because of the descriptive nature of this study, the question concerning the competing demands could not be asked directly. This study asked how they self-managed their diabetes and how caring for a PWD was difficult. When I was recruiting it became increasingly evident that if I asked about the dementia caregiving first, they did not want to speak with me. When I began the conversation asking about their self-management behaviors only, they shared information about their behaviors of SMD. Once the PI felt a relationship of trust had been established, questions about caregiving difficulty were

introduced and the CRA survey was completed by the participant, with less hesitancy. A hypothesis generated from this study is that further research is needed to determine if the variables showing association with the dependent variables, medications, diet, caring for grandchildren, age, caregiving performance difficulty, glucose testing, years with diabetes and education would demonstrate an association in larger and more diverse samples. If they do, research is needed to be developed and tested to address the potentially modifiable variables which are caring for grandchildren, diet, medications and finances. What ways are there to help people invest more in self-care even when their diabetes is less severe as a preventative measure? Longitudinal rather than cross sectional studies are needed to determine if these independent variables come before the HbA1c or if it's the level of the HbA1c that triggers the behaviors. This cross sectional study only looks at associations; longitudinal studies are needed to assess causal relationships among the variables. Using a more robust probability level, will determine what variables would be important. Another extension of this research might be caregivers of persons of others than persons with dementia and men.

Implications for Practice

The implications of the study findings for practice are plentiful. There is increased need for awareness of how prevalent diabetes is in African American women (ADA, 2012). Several of the women in the study were obese, did not exercise, and did not follow a healthy diet. Health promotion clinics staffed with nurses, diabetes educators, nurse practitioners, and physicians could consider the research findings with caregiving grandmothers with diabetes as they contemplate the plan of care. Caregiving grandmothers are found to be better at self-management of diabetes activities.

Additionally, these caregiving grandmothers in the study are caring for persons with dementia.

A possible explanation for the motivation to self-manage better in the current study could be to sustain their ability to raise their grandchildren. Health professionals can enhance self-management of diabetes behaviors in caregivers of persons with dementia when they better understand the intergenerational and other caregiving responsibilities of African American women with diabetes. Clinicians can assist with the burden of caregiving by handing out resource materials on how to access the Alzheimer's Association's Care Navigation program, help hotline number, and caregiver support group meetings.

Implications for Education

The implications of the study for education of nurses can be applied in several arenas. Nursing undergraduate, graduate, and continuing education programs, can benefit from the new knowledge of the challenges of self-management of diabetes in minority populations. Nursing educators can apply the evidence in the study as they teach nursing students about earning trust in minority populations. This is the first step to enable further inquiry which can result in better nursing care of the patient with diabetes who also has caregiving responsibilities for a person with dementia. Teaching nursing students about research with African American populations requires knowledge of the networking and recruitment strategy used in this study with regaining entry and perhaps trust, come with the establishment of a relationship with the gatekeeper and pastor. Knowing this stepwise method of access to the women of color, nursing students will now know more about how

to approach them in order to get their health history, daily routine, self-management of diabetes behaviors and challenges.

Nursing students will learn to develop comprehensive family care plans, rather than individual care plans to target the self-management of diabetes, co-morbidities of both the caregiver and the care recipient, and dementia care. The students now know that the increased responsibility of caring for a person with dementia requires priority setting in order to effectively manage their diabetes. Further studies need to explore how priorities are set to meet these competing demands. A comprehensive list of comorbidities in the caregivers documents additional care concerns of older African American women with diabetes. Students need to learn how to manage complex care needs and plan for longitudinal self-care management.

Students need to be knowledgeable of the cost of diabetes supplies, state and federal funding mechanisms and how to access community resources to aid in better self-management behaviors. Finally, nursing students need more education on dementia care and caregiver support mechanisms. Coping with dementia care at home can be fostered in culturally appropriate environments, such as the church or community-based nurse-led clinics.

Implications for Policy

In the interest of public health, the rising prevalence of diabetes and dementia in the African American population, policymakers should use the evidence in this study concerning caregiving grandmothers with diabetes, comorbidities and caregiving performance difficulty, with others findings to address the finances needed to care for a person with dementia while self-managing diabetes. Caregiving grandmothers with

diabetes making less than \$30,000 annually were found to have decreased odds of having their glycemic status in good control. As these women age and try to manage their diabetes and additional comorbidities, the cost of self-management is a concern, especially because of the life expectancy of persons with dementia. We know that poverty leads to poor health outcomes (Williamm & Lu-Walker, 2009). We also know these non-paid caregivers are contributing exponentially to the nations' healthcare system by keeping their elders at home rather than a nursing home (Dilworth-Anderson and Colleagues, 2005). Another very important hypothesis generated is that these findings inform public health officials, Surgeon General, and Health and Human Services Secretary that more needs to be done to help caregivers of persons with dementia improve self-management of diabetes activities behavior, as it is more predictive of self-management behavior than HbA1c levels. The evidence could support development of a comprehensive task force to address disparities in the payment of health care services for chronic illness management for caregivers of persons with dementia in minority populations, especially those making \$30,000 or less annually. This task force could also explore ways to compensate these family caregivers that receive \$30,000 or less annually. This result came from a sample of 50 family caregivers with diabetes. Imagine the impact on finances for the millions of older African American women caregivers of persons with dementia!

Many of the participants in the dissertation study were single, head of household or widowed. They relied on Social Security and Medicaid benefits. Medicare is only available to persons age 65 and older. The study found caregiving grandmothers who were under the age of 65, (36%) who are widowed and head of household, with

additional responsibilities of managing their diabetes while providing dementia care. These women under age 65 are not eligible to receive Medicare assistance to pay for blood glucose testing supplies, and this affects their ability to manage the diabetes appropriately. Many low income African Americans and some middle income African Americans are uninsured. Having no insurance and low socioeconomic status in general is a barrier to self-management as people may not have the funds necessary to practice self-management of diabetes behaviors (Office of Minority Health, 2008).

In the Affordable Care Act, President Obama has as recently as June 14, 2013 addressed the National Plan on Alzheimer's disease charged to improve early diagnosis, coordination of care, and treatment of Alzheimer's disease. An important finding in the study uncovered a cultural belief or interpretation of the Bible that informs how African Americans view dementia. Policymakers should use the study findings to address issues effecting early diagnosis of Alzheimer's disease, as it impacts self-management of diabetes activities. The study highlights relationships of better self-management of diabetes and coordinating care through state and federal systems, is bound to improve self-management behaviors of this population. The dissertation study addresses a gap in the literature on barriers to self-management of diabetes for African American women caregivers of persons with dementia, as well as facilitators. The results of the study will inform policymakers of the challenges faced by an understudied population, with increasing worth and demand for their caregiving sustainability.

Recommendations Based on My Professional Experience

Recommended Implications for Research

Nurse scientists should pursue answers to questions such as: What do older African American women caregivers of persons with dementia see as barriers to better self-management of diabetes?; What community services would help African American caregivers of persons with dementia better manage their diabetes? More descriptive work is needed prior to the design and testing of interventions to answer the questions just posed. After adopting these approaches to recruitment and inquiry the following question could be answered: How can the daily competing demands of self-management of diabetes and caring for a person with dementia by older African American women caregivers be prioritized, resulting in better self-care behaviors?

Recommended Implications for Practice

Although the years caring for a person with the dementia and hours caregiving are not associated with HbA1c or self-management of diabetes activities in this study, the competing demands of caring for a family member with dementia, caring for grandchildren, and managing their diabetes, should be considered when these clients are seen in the hospital, doctor's office, or community clinics. It also could be built on to motivate persons to increase their self-management activities. We know from the literature that African American families have intergenerational households (Dilworth-Anderson, et al., 2005). The same situation was found in this study also.

Health care agencies could develop an interdisciplinary program between dietary and social service personnel to link the women caregivers with neighboring food pantries that would agree to package food consistent with diabetic diets with recipe cards in each

basket of food. In addition to the recipes, helpful tips on cooking for the family, maintaining a healthy weight, and performing routine moderate exercise could be in the food baskets also.

The cost of self-management of diabetes must be considered by practitioners also. This point is consistent with the dissertation study findings as the participants who were taking medications had better HbA1c levels and self-management of diabetes activities than participants who managed with diet only. Questions must be asked about the patient's financial ability to purchase supplies for monitoring blood sugars, adhering to the prescribed diet and medication regime. Samuel-Hodge et al. (2005) found low income African American women put other's needs first and delay buying glucose monitoring supplies, and medications to manage their diabetes. These women were also less likely able to afford nutritious foods needed to maintain better glycemic control.

Naylor (2004) suggests transitional healthcare systems improve health outcomes in older adults with diverse needs. A transitional health care program to improve outcomes in this population would provide the follow-up supervision to assess the self-management behaviors of the caregivers. In the current study, aging caregiving grandmothers were found to be good managers of their diabetes. In future intervention research, the grandchildren could assist the grandmothers with utilizing technology to maintain good self-management of their diabetes. This could be accomplished with the technology of smartphones allowing for communication and monitoring of blood glucose levels. Domidowich, Lu, Tamler, and Bloomgarden (2012), examined the uses of applications for smartphones to aid in self-management of diabetes. The HealthSeeker application utilizes the social media sites Facebook and Twitter to promote lifestyle

changes and education on diabetes and proper nutrition. Currently, no outcome information from this intervention is available. This avenue of telemedicine could be applied to older African American women with diabetes. Because of their age, an intergenerational technique of having teenagers teach the adults how to use the social media sites to improve self-management behaviors, document glucose results, and socialize while staying home to provide care to their family member with dementia, will enhance their control over their diabetic condition, allow them to send their glucose results to the physician for closer monitoring of their condition, and alleviating the isolation that accompanies caring for a person with dementia. The self-management of diabetes and caring for persons with dementia in the African American population is a complex health care dilemma requiring a systematic approach.

Recommended Implications for Education

Nursing students will learn to develop comprehensive family care plans, rather than individual care plans to target the self-management of diabetes, co-morbidities of both the caregiver and the care recipient, and dementia care. The students now know that the increased responsibility of caring for a person with dementia requires priority setting in order to effectively manage their diabetes. Further studies need to explore how priorities are set to meet these competing demands. A comprehensive list of comorbidities in the caregivers documents additional care concerns of older African American women with diabetes. Students need to learn how to manage complex care needs and plan for longitudinal self-care management.

Nursing students need to learn to construct interventions that will benefit the patients with diabetes by incorporating the patient's home environment. The home

environment includes the neighborhood, resources in the neighborhood, number of people in the household, any caregiving responsibilities, and the participant's work status.

Also in this study the participants had more difficulty when they tried to control the diabetes with diet only. An example for a practicum experience for the BSN students might plan a potluck on a Sunday afternoon at the church. Prior to the potluck the students can work with the women of the church on diabetic friendly recipes to bring to the potluck.

Masters Science Nursing (MSN) students in systems administration tracks didactic education can be enhanced with case studies concerning the dual responsibility of self-management of diabetes and caring for a person with dementia by older African American women. A practicum experience for MSN students can be to use the case study scenarios, find community resources, communicate with agencies who will serve the clients, and form linkages with the agencies, to promote seamless care in African American communities. This learning experience will foster systematic approaches to problem-solving by using available resources and knowledge of how to network to find additional resources which can aid in better self-management of diabetes in older African American women caregivers of persons with dementia.

Doctorate nursing practice (DNP) curriculum may be enhanced didactically by theory in African American history, health beliefs, geropsychiatric nursing and unconscious discrimination. Practicum experience in African American church clinics will give them experience with managing the person's diabetes while considering their caregiving responsibilities at the same time. The DNP nurse practitioner students can learn how to accomplish these skills by applying NIC and NOC standardized nursing

languages for evidence-based practice by using the technology of smartphones and social media to allow the DNP student experience with monitoring outcomes of self-management of diabetes over time. This mechanism of caring, critical thinking, professional practice, and communication will engage their clients in dialog to foster communication and documentation of how the client is managing the diabetes at home. Knowing the history and current views on unconscious discrimination in healthcare (Williamms, & Lu-Walker, 2009) will enhance their ability to be effective in offering their older African American female clients the appropriate information on diabetes management and dementia caregiving. This will ensure the client's understanding of the disease process, potential complications like amputations (Jenkins et al., 2011), differences in perceptions and expectations for care (Cagle, Appel, Skelly, & Carter-Edwards, 2002) and accounting for economic constraints (Williamms, & Lu-Walker, 2009) which may affect the ability of older African American women caregivers of persons with dementia to properly self-manage their diabetes, resulting in more positive outcomes.

The Institute of Medicine (IOM) 2012 report titled *The Mental Health and Substance Use Workforce for Older Adults: In Whose Hands?* identified the need for narrowing the gap in the health care system and a collaborative education on geropsychiatric care of older adults to meet the demand. Expert nurses along with the John A. Hartford Foundation founded the Geropsychiatric Nursing Collaborative (GPNC) to “improve the mental health of older Americans, by preparing nurses at all levels in geriatric mental health” (Beck, Buckwalter, Dudzik, & Evans., 2011, p. 237). The GPNC developed a Portal of Geriatric Online Education's (POGOe) website (<http://pogoe.org>)

with geropsychiatric nursing competency enhancements (GPNCE) to prepare nurses at all levels to practice in collaboration with other disciplines. DNP curriculums should include the POGOe website for dementia care and caregiver support tools and modules, to bridge gaps in the healthcare system and improve outcomes for African American women caregivers of persons with dementia. In this study the impact on finances had a relationship with the caregiver's ability to self-manage their diabetes, meaning it made self-management more difficult. The POGOe website is framed with an interprofessional model, where DNP students can learn how to reach out to clergy, social workers, nutritionists, personal trainers, and financial assistance agencies, to enhance the client's health. One hypothesis generated from the study is that chances are that by supporting the client's mental health needs, their physical needs of self-management of diabetes may also be met.

To provide geropsychiatric nursing and interprofessional educational practicum experiences for DNP students, they could practice in simulation laboratories (Harris, Mayo, Balas, Aaron, & Buron, 2013) with scenarios of African American women caregivers of persons with dementia. Because caring for a person with dementia requires a comprehensive approach, the opportunity to take complex family caregiver issues such as multiple caregiving roles, financial burden, and the stigma of a dementia diagnosis, learning to work with other disciplines while in school is consistent with the IOM Report (2012). This type of practicum experience will allow the MSN students to care plan by inverting the problems into culturally sensitive interventions (Tripp-Reimer et al., 2001). The experience can lead to culturally congruent caregiver support and possibly better self-management of diabetes. The scenarios can be written by the PhD students who

study caregiver outcomes with an interdisciplinary focus. Those PhD students interested in Gerontological nursing will benefit from curriculums that include practicum experiences with expert nurse scientists in chronic disease management and dementia caregiver support in African American women, so they can teach research in these specialty areas.

Minorities are poorly represented in the nursing (American Association of Colleges of Nursing, 2012). The recruitment of more African American students and lower socioeconomic economic students into nursing can aid in better self-management of the caregiver's diabetes, because we know that people relate better to persons more like themselves (The Sullivan Commission on Diversity, 2012). These nursing students will establish trusting relationships with their patients more rapidly, facilitating diabetes education and better self-management behaviors.

Insight on how African American s view dementia was unveiled to the PI by a minister at the church in South Holland, Illinois. The biblical interpretations of verses specific to behaviors consistent with dementia prevent caregivers from seeking a diagnosis to confirm Alzheimer's disease and from seeking caregiver support. African American women keep their family member with dementia at home for as long as possible; the concern for the caregiver's self-management of health requires culturally-specific individualized care planning. This type of theory could be taught in a geropsychiatric course to senior nursing students, with a practicum experience in African American churches, with older African American women with diabetes who care for persons with dementia. This knowledge will prepare the BSN student to approach these

older African American women appropriately and be most successful at helping them better self-manage their diabetes.

Recommended Implications for Policy

Access to care is crucial to helping vulnerable populations such as African Americans with diabetes self-manage their chronic conditions. The Office of Minority Health (2008), reports that African Americans have more chronic conditions than other populations. The data collected concerning co-morbidities of the participants, reflects the seriousness of the Office of Minority Health Report (2008). Another hypothesis generated from the study are the concerning points that because these women are older, have diabetes and other co-morbidities while caring for a family member with dementia, access to systems of culturally competent health care must be accessible to people without insurance and those just above the poverty level who are not eligible for Medicaid. The adult income eligibility to receive Medicaid benefits limits applications as a percent of the Federal Poverty level as of January 2013. Those limits include \$19,000 annually for a family of three and 11,170 annually for an individual. Currently the Governor of Illinois Patrick Quinn has supported Medicaid expansion and it has passed both legislative bodies. The finalization of this legislation into law should improve access to care for older African American women with diabetes who are caregivers of persons with dementia.

Conclusions

The study was a first attempt at describing how older African American women self-manage their diabetes while at the same time care for a family member with dementia. The PI looked at HbA1c as an outcome variable and the extent that caregiving

activities prevent the appropriate self-management of diabetes activities to occur. The reason for the study was to look at caregiver self-management of diabetes and the relationship to self-care activities to HbA1c levels. The study used quantitative methods. The cross-sectional study informs nursing science of facilitators and barriers of self-management of diabetes for older African American women caregivers of persons with dementia. An important gap has been addressed in the sustenance of older African American women caregivers of persons with dementia. Evidence of the barriers and facilitators to self-management of diabetes for older African American women caregivers of persons with dementia brings to the forefront contextual and cultural considerations for nursing education, clinical practice, intervention research, and health policy application of our nation's elders.

Findings of this study indicate the best association of self-management of diabetes is realized with the Summary of Diabetes Activities Scale. This scale measures the self-management of diabetes daily activities and is a better indicator of how well a participant manages their diabetes rather than HbA1c alone. Future studies will use a more comprehensive measure of diabetes self-management activities to measure the participant's adherence to their physician's recommendations. The Caregiving Reaction Assessment measures caring for a family member with dementia. Caregivers of grandchildren actually perform better with self-management activities, yet they have worse diabetes according to their elevated glycemic status. Evidence exists to support possible intervention research to help improve the self-management of diabetes in this population. The multifactorial issues of importance in self-management of diabetes for older African American women as they age through the process of daily management of

self-care diabetes activities, manage their comorbidities, and care for a family member with dementia have been brought to the forefront. The significant contribution to the literature is the two public health issues of diabetes and dementia caregiving in older African American families, should drive healthcare policy, advocacy, and the quality care provision to a population who struggles with mistrust of the healthcare system (Ranjit et al., 2007). The mistrust in the healthcare system has led to poor decision making, amputations, and poor overall health of many older African American women.

Because caring for a person with dementia can go on for years, the aging African American female caregiver will have increased difficulty with self-management of diabetes activities. Future studies will include a larger sample of older African American women with diabetes. The recruitment methods will be adapted to first focus on the caregiver's general health before asking them about aspects of caring for a family member with dementia. Also, caregivers will be recruited at venues other than caregiver support groups in order to reach vulnerable caregivers who are not currently receiving any type of support. Mixed method inquiry will allow for qualitative data to explain decision making in the management of diabetes in this population. This approach will lead to a framework which facilitates better self-management of diabetes in African American women caregivers of persons with dementia. The evidence of future studies will be of particular interest to the Alzheimer's Association and the American Diabetes Association as we attempt to learn more concerning the competing demands of caring for a family member with dementia and self-managing diabetes in older women of all races. The results of this study confirm the original hypothesis that there are relationships

among caregiver performance difficulty, diabetes self-management and glycemic status in older African American women caregivers of persons with dementia.

APPENDIX A
INSTRUMENTS

The Summary of Diabetes Self-Care Activities

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

ACTIVITIES	1	2	3	4	5	6	7
DIET							
How many of the last SEVEN DAYS have you followed a healthful eating plan?							
On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?							
On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?							
On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?							
EXERCISE							
On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).							
On how many of the last SEVEN DAYS did you participate in a specific exercise Session (such as swimming, walking, biking) other than what you do around the house or as part of your work?							
BLOOD SUGAR TESTING							
On how many of the last SEVEN DAYS did you test your blood sugar?							
On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?							
FOOT CARE							
On how many of the last SEVEN DAYS did you check your feet?							
On how many of the last SEVEN DAYS did you inspect the inside of your shoes?							
SMOKING							
Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?							
0. No							
1. Yes. If yes, how many cigarettes did you smoke on an average day?							
2. Number of cigarettes							

Caregiver Reaction Assessment

FACTOR	Strongly Agree	Moderately Agree	Agree	Moderately Disagree	Strongly Disagree
	5	4	3	2	1
Impact on Schedule (Factor 4)					
Stop work to care					
Eliminate from schedule					
Activities centered on care					
Visit family/friends less					
Interruptions					
Caregiver's Esteem (Factor 1)					
Privilege to care					
Want to care					
Enjoy caring					
Caring makes me feel good					
Caring is important to me					
Never do enough to repay					
Resent having to care (reverse)					
Lack of Family Support (Factor 2)					
Difficult to get help					
Feel abandoned					
Family left me alone					
Family works together (reverse)					
Others dump caring					
Impact on Health (Factor 5)					
Physical strength (reverse)					
Healthy enough to care (reverse)					
Health has gotten worse					
Tired all the time					
Impact on Finances (Factor 3)					
Difficult to pay					
Finances are adequate (reverse)					
Financials strain on family					
Eigenvalue					
Percent					

Participant Demographics

Annual Income		
Education		
Years with diabetes		
Age		
Insulin		
Insulin and tablets		
Tablets only		
Diet only		
Glucose testing routine		
Years caring for a person with dementia		
Caring for children		
Caring for grandchildren		
Comorbidities of the caregiver		

Questions

1. What is your annual income?
2. What is the highest level of education you received?
3. How many years have you had diabetes?
4. How old are you?
5. Do you take insulin, tablets or both?
6. Do manage your diabetes with diet only?
7. How often do you check your blood glucose?
8. How many years have you cared for your family member with dementia?
9. Do you care for children at home?
10. Do you care for grandchildren at home?
11. Do you have any other health conditions besides diabetes?

Time Spent Caregiving

Hours/day	S	M	T	W	Th	F	Sa

APPENDIX B
PSYCHOMETRICS OF THE STUDY

PSYCHOMETRICS OF THE STUDY

Variables	Measures	Psychometrics	Time
Glycemic Status	Glycosolated Hemoglobin	Reliability- .978, interclass correlation of dried spot with venipuncture, Criterion Validity- Gold Standard	8 min.
Diabetes Self-Management Activities	Summary of Diabetes Self-Care Activities Scale	Reliability- IIC 0 .47-0.67, TRTR-moderate. Criterion Validity moderate to high, Most widely used tool to measure SMD Sensitive to change	10 min
Performance Difficulty Caregiving	Caregiver Reaction Assessment	Reliability-Cronbach alpha .81-.90, Construct validity	10 min
Caregiving Intensity	Hours of caregiving per day		3 min
Age, education, income, work outside home, years with diabetes, years of caregiving, diabetes medication, Comorbidities	Demographic data sheet		10 min

APPENDIX C
INFORMED CONSENT

RESEARCH SUBJECT**INFORMED CONSENT FORM**

Protocol Title: Describing the Self-Management of Diabetes by Older African American Caregivers of Persons with Dementia

Principal Investigator: Charlene S. Aaron PhD(c), RN
Assistant Professor
PhD Candidate, University of Iowa
Illinois State University, Mennonite College of Nursing
Campus Box 5810
Normal IL 61790-5810
309 438-7116

Emergency Contact: Charlene S. Aaron PhD(c), RN
309 438-7116

Why am I being invited to volunteer?

You are being invited to participate in a research study. Federal regulations require that you are informed of the research you are being invited to volunteer for and your signature indicating that you have been informed about the research. You are being invited to volunteer since you meet the requirements for enrollment into this study. Your participation is voluntary which means you can choose whether or not you want to participate. Before you can make your decision, you will need to know what the study is about, the possible risks and benefits of being in this study, and what you will have to do in this study. The researcher is going to talk to you about the research study, and they will give you this consent form to read. If you decide to participate, you will be invited to sign this form. Your signature on this form is voluntary and does not waive any of your legal rights or make any institutions or persons involved in this research any less responsible for your well-being. Your refusal to participate in this study has no consequences.

Who is the Principal Investigator for this Study?

Charlene S. Aaron PhD(c), RN
Assistant Professor
PhD Candidate, University of Iowa

PhD Candidate
Illinois State University, Mennonite College of Nursing
Campus Box 5810, Normal IL 61790-5810
309 438-7116

What is the purpose of this research study?

The purpose of this study is to examine how older African Americans with diabetes self-manage their diabetes while providing care to persons with dementia.

How long will I be in the study?

You will be in this study no more than 60 minutes while you fill out short surveys on managing your diabetes, 2 surveys on caregiving, answering 2 questions on diabetes self-management activities, and allowing a fingerstick to be drawn by the PI who is a registered nurse.

How many other people will be in the study?

Up to 80 people will participate in the study.

What is involved in this study?

Participation in this study will involve filling out 3 short surveys, one on self-management of diabetes, the other 2 on caregiving, and answering 2 questions concerning diabetes self-management activity performance. Also a fingerstick will be performed by the researcher who is a registered nurse, for the purpose of determining your blood sugar average over the last 3 months.

What are the possible risks or discomforts?

The potential risks are that you may notice that you are not managing your diabetes well. This may cause some emotional distress. Also, the fingerstick may be slightly painful, even though you perform this procedure on yourself several times a week or daily at home.

What are the possible benefits of the study?

The Researcher will be able to learn the barriers and facilitators to self-management of diabetes in African Americans who care for persons with dementia. This knowledge can inform appropriate interventions leading to improved self-management of diabetes in larger populations of older African American caregivers of persons with dementia.

What other choices do I have if I do not participate?

Instead of being in this study, you could choose not to participate in this study.

Will I be paid for being in this study or will I have to pay for anything?

You will receive a check for \$25.00 from the University of Iowa for your time involved in participating in this study. There are no costs to you.

When does the Study end?

You can stop participating and/ or refuse to answer any question at any time. This study is expected to end after each of the interviews, surveys and fingerstick have been completed. The process should take no longer than an hour. If you decide not to participate, you are free to leave the study at any time. Withdrawal will not interfere with your payment.

Who can see or use my information? How will my personal information be protected?

Your privacy is important to us. Your name will never go on any of the information I am collecting. The only personal information to be collected is your age, education and income. Interviews, surveys, and the fingerstick results will be linked with a code number, known only to the researcher, and there is no link between the code number and your name. All of the data will be secured in the PI's locked office.

What if I change my mind?

You may withdraw from the study for any reason simply by telling the Charlene Aaron, the Principal Investigator. If you decide not to participate, you are free to leave the study at any time.

Who can I call about my rights as a research subject?

If you have questions regarding your participation in this research study or if you have any questions about your rights as a research subject don't hesitate to speak with the Principal Investigator, Charlene S. Aaron PhD (c), RN, a 309 438-7116 or csaaron@ilstu.edu. If you have questions concerning your rights as a research subject, you may also contact the Research Ethics and Compliance Office at Illinois State University at 309-438-2529 or rec@ilstu.edu

When you sign this form, you are agreeing to take part in this research study. This means that you have read the consent form, your questions have been answered, and you have decided to volunteer.

A copy of this consent form will be given to you.

Printed Name of Subject

Signature of Subject

Date

**Printed Name of Person
 Obtaining Consent**

Signature

Date

APPENDIX D
HUMAN SUBJECTS REVIEW

October 11, 2012

Charlene Aaron
5810 Mennonite College of Nursing

Thank you for submitting the IRB protocol titled “**The Self-Management of Diabetes in African-American Women Caregivers of Persons with Dementia**” for review by the Illinois State University Institutional Review Board (IRB). The IRB has **Approved** this research protocol following an **Expedited Review** procedure. You may begin this research.

This protocol has been given the IRB number **2012-0241**. This number should be used in all correspondence with the IRB. You may proceed with this study from **10/10/2012** to **10/01/2013**. You must submit a continuation request and receive approval prior to continuing your research beyond this expiration date.

Please also note that research protocols may be approved for continuation for a maximum of three years from the original date of approval in periods not to exceed one year. Research protocols having had three years of approval must be resubmitted and reviewed as new proposals.

This approval is valid only for the research activities, timeline, and subjects described in the above named protocol. IRB policy requires that any changes to this protocol be reported to, and approved by, the IRB before being implemented. You are also required to inform the IRB immediately of any problems encountered that could adversely affect the health or welfare of the subjects in this study. Please contact Kathy Spence, Assistant Director of Research at 438-2520 or myself in the event of an emergency. All other correspondence and questions should be addressed to:

Institutional Review Board
Campus Box 3330
Hovey Hall, Room 307
Telephone: 438-2529
E-mail: rec@IllinoisState.edu

IRB Deferment Agreement for an Individual Protocol

Name of Research Project: The Self-Management of Diabetes in African American Women Caregivers of Persons with Dementia
 Investigator: Charlene Aaron
 Sponsor or Funding Agency, if any: _____

Name of Institution Providing IRB Review: Illinois State University Institutional Review Board (IRB)
 Address, Telephone number, or other pertinent contact information: Institutional Review Board
 Campus Box 3330 Hovey Hall, Room 307
 Telephone: 438-2529 E-mail: rec@IllinoisState.edu
 Office for Human Research Protections (OHRP) Assurance Number:
 IRB Registration Number:

Name of Institution Relying Upon IRB Review: The University of Iowa
 Address, Telephone number, or other pertinent contact information: IRB\Human Subjects Office; 340 CMAB, Iowa City, IA 52242 Phone: 319-335-6564 Fax: 319-335-7310 Email: irb@uiowa.edu
 Office for Human Research Protections (OHRP) FWA00003007
 Assurance Number:
 IRB Registration Number: IRB00000099 (IRB-01)
 IRB00000100 (IRB-02)

The Officials signing below agree that The University of Iowa may rely on the review, approval, and continuing oversight provided by **Illinois State University Institutional Review Board (IRB)** for the above-named project only. The review, approval, and continuing oversight performed by the **Illinois State University Institutional Review Board (IRB)** as the IRB of record will satisfy the requirements of the HHS regulations for the protection of human subjects at 45 CFR 46, as well as the human subjects protection requirements of the University of Iowa's OHRP-approved FWA.

If the above named project is greater than minimal risk, relevant minutes of the **Illinois State University Institutional Review Board (IRB)** meetings shall be made available to The University of Iowa upon request. As the IRB of record, Illinois State University Institutional Review Board (IRB) acknowledges and accepts its continuing responsibility to oversee the conduct of research for the above-named project, in compliance with all applicable federal, state and local laws and regulations, including, without limitation, those relating to financial disclosure and conflict of interest, misconduct in science, non-discrimination, certification of non-debarment and suspension, and reporting of unanticipated problems. Illinois State University Institutional Review Board (IRB) agrees to verify all credentialing and qualifications are accurately represented and current for each individual that is engaged in research under the above named project.

Illinois State University Institutional Review Board (IRB) agrees to notify the University of Iowa IRB of any the following: IRB termination or suspension of a study; instances of serious or continuing noncompliance with the federal regulations; initiation of any for-cause audit or investigation of a study; targeted regulatory inspections of the above named project; and any other matter that comes to the attention of the **Illinois State University Institutional Review Board (IRB)** that adversely affects compliance with applicable regulations and laws governing human subjects research. The **Illinois State University Institutional Review Board (IRB)** shall also notify the University of Iowa IRB of its decisions to approve, disapprove, or recommend modification for the above-named project. Illinois State University Institutional Review Board (IRB) further agrees to notify the University of Iowa IRB of reports of actions that are sent to the Food and Drug Administration (FDA) or the Office of Human Research Protections (OHRP), such as (a) any unanticipated problems involving risks to subjects or others; (b) any serious or continuing noncompliance with FDA regulations or with DHHS regulations at 45 CFR Part 46, as applicable, or the requirements or determinations of the IRB of record; and (c) any suspension or termination of IRB approval.

Version Date: 2/2010

When federal funding is a funding source for the above named project, the University of Iowa shall amend a Federal Wide Assurance ("FWA") listing the above named IRB of record as providing IRB oversight for the above named project. Each IRB/Institution named on this agreement shall abide by the terms of its assurance and its responsibilities as set forth in 45 CFR 46.

The University of Iowa agrees to defer to the Illinois State University Institutional Review Board (IRB) in acting as the HIPAA Privacy board for the above named project only and, where appropriate, approving requests for waivers of authorization and documenting the consideration of waiver criteria and approval of such requests; and (ii) Maintaining records documenting waivers of authorization for individual research studies and making those records available to The University of Iowa upon request.

The University of Iowa will remain responsible for ensuring compliance with the determinations of the Illinois State University Institutional Review Board (IRB), as well as with the terms of its own OHRP-approved FWA.

This document should be kept on file at both institutions and must be provided to OHRP upon request. This Agreement is in effect for as long as each party maintains a current FWA (when applicable) or until the termination of this Agreement by either party. The University of Iowa expressly retains the right to terminate this Agreement and revoke its deferral for IRB review at any time and to conduct its own review of the study. Illinois State University Institutional Review Board (IRB) agrees to indemnify, defend, and hold harmless the University of Iowa, its employees, officers, and agents, its IRB, the State of Iowa, and the Iowa Board of Regents from and against any and all claims, suits, or damages arising from a breach of this Agreement by the Illinois State University Institutional Review Board (IRB) or any of its employees.

University of Iowa IRB Chair – Printed Name J. Andrew Bertolatus, MD

University of Iowa IRB Chair – Signature _____ Date _____

University of Iowa Authorized Institutional Official – Printed Name James C. Walker Ph.D

University of Iowa Authorized Official - Signature _____ Date _____

Illinois State University Institutional Review Board (IRB) Authorized/Signatory Official Printed Name *Dany Heaney* Date 2/11/13

Illinois State University Institutional Review Board (IRB) Authorized/Signatory Official Signature *Dany Heaney* Date 3/19/13

APPENDIX E
PERMISSION LETTERS

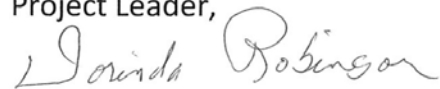
Covenant United Church of Christ
1130 E. 154th Street
South Holland Illinois 60473-1110

May 17th, 2012

To Whom It May Concern

My name is Dorinda Robinson and I am a member of Covenant United Church of Christ and the project leader of Caring Together-Living Better program which offers free services to caregivers. I have agreed to introduce Charlene Aaron to members of the church, with our Pastor Rev. Dr. Ozzie E. Smith Jr.'s previous approval. Ms. Aaron will be encouraging the members to participate in her research on Alzheimer and dementia which will be a significant help to the black community.

Project Leader,



Dorinda Robinson



Covenant United Church of Christ
 1130 E. 154th Street
 South Holland, Illinois 60473-1110
 Telephone 708.333.5955 Fax 708.333.4220

May 25, 2011

Rev. Dr. Ozzie E. Smith, Jr.
 Senior Pastor

•
Rev. Rhoda J. Barnes
 Assistant to the Pastor
 Director of Pastoral Services

Rev. Gwendolyn Kirkland
 Associate Pastor of Stewardship

Rev. Andrea Lasticly
 Associate Pastor

Rev. Terrill Murff
 Minister of Youth

Rev. Melody Seaton
 Associate Pastor Biblical Studies
 Curriculum/Pastoral Counseling

Randall Johnson
Brian Smith
 Assistant Directors of Music

•
Charleen Mills
 Chief Financial Officer

Kathy Harris Brown
 Administrative Assistant

Constance Mitchell
 Church Clerk

Seena Brodnax-Brown
 Church Clerk

•
Mark Hall
Tiffany Johnson
Stanley Richardson
 Media

Charlene S. Aaron, Ph.D. (c), RN
 Assistant Professor, Illinois State University
 Mennonite College of Nursing
 221 Edwards Hall
 Campus Box 5815
 Normal, IL 61790-5815

Dear Dr. Aaron:

Grace, mercy, and peace to you!

It is with pleasure that I grant permission for you to conduct research related to the health state of caregivers of loved ones with dementia. As mentioned in your letter dated May 12, 2011, the study will begin either the summer or fall of 2011. I look forward to the time and the experience.

Sincerely,

Rev. Ozzie E. Smith, Jr.

I thank my God every time I remember you, Philippians 1:3

APPENDIX F
ANNOUNCEMENT LETTER

RESEARCH PARTICIPATION NEEDED!!!

African American female doctoral student from the University of Iowa wishes to
Recruit African American women age 50 and older with diabetes and who are
Caregivers of person with dementia or behaviors consistent with dementia to
Participate in a research study concerning womens' health.

- ❖ The nurse researcher is interested in learning more about the health of Africa American women who provide care to a family member with dementia.
- ❖ Your participation will help the medical and nursing field learn more about the health of African American women with diabetes and how they manage self-care while providing time intensive dementia care to family members.
- ❖ If you fit the description above please watch for the dates to sign up to participate. Interviews will be conducted at Covenant United Church of Christ, South Holland, Illinois.



APPENDIX G
RECRUITMENT LETTER

RESEARCH PARTICIPATION NEEDED!!!

African American female doctoral student from the University of Iowa wishes to
Recruit African American women age 50 and older with diabetes and who are
Caregivers of person with dementia or behaviors consistent with dementia to
Participate in a research study concerning womens' health.

- ❖ The nurse researcher is interested in learning more about the health of African American women who provide care to a family member with dementia.
- ❖ Your participation will help the medical and nursing field learn more about the health of African American women with diabetes and how they manage self-care while providing time intensive dementia care to family members.
- ❖ If you fit the description above please watch for the dates to sign up to participate. Interviews will be conducted at Covenant United Church of Christ, South Holland, Illinois.
- ❖ 5. p.12, Risk of participation: The potential risks are that you may notice that you are not managing your diabetes well. This may cause some emotional distress. Also, the fingerstick may be slightly painful, even though you perform this procedure on yourself several times a week or daily at home.



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