FACTORS ASSOCIATED WITH DIABETES MANAGEMENT

IN LOW-INCOME FEMALE CAREGIVERS: A FEASIBILITY STUDY

by

RACHEL LAUDEL

(Under the Direction of Jung Sun Lee)

ABSTRACT

Low-income female caregivers disproportionately experience higher rates of food insecurity and type 2 diabetes. This feasibility study aims to understand the status of and factors associated with diabetes management in low-income female caregivers while establishing a partnership with a community organization serving low-income populations. Key factors considered in this study include food insecurity, diet quality, caregiving burden, and diabetes-related emotional distress. This was a cross-sectional study of in-person interviews and medical record reviews. Four women participated and reported overall poor adherence to recommended diet and exercise, and poor mental health. One of the four women had poor glycemic control, and experienced lower food security, poorer diet adherence and poorer mental health than others. This study encountered many barriers in recruitment. It is recommended that future studies utilize multiple avenues for recruitment and partner with multiple community organization. This study lays the groundwork for future studies that target this hard-to-reach population.

INDEX WORDS: low-income; female caregivers; diabetes management; glycemic control; food insecurity; dietary intake; diet quality; caregiving burden; stress; diabetes-related distress; feasibility; safety net clinic

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by

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DEDICATION

This project is dedicated to my family, who loved me and supported me. You have always believed in me, even when I doubted my own abilities. You all have each individually contributed to the success and completion of this thesis project. I dedicate this work to you because you are the reason all of this is possible. I love you all with all of my heart.

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CHAPTER 1

INTRODUCTION

Female caregivers, defined here as one who is responsible for attending to the needs of a child or adult child, disproportionately experience poverty and food insecurity in the United States (De Navas-Walt et al 2014; Coleman-Jensen et al 2014b; Ellis and Simmons 2014). Unlike individuals without dependent children, caregivers have the added responsibility of providing care physically and emotionally for their children. Limited resources make it even more difficult to meet the responsibilities of caregiving. For caregiving grandmothers, specifically, the demand of childcare and material hardship can negatively affect their health (Hugh et al 2007). More specifically, low-income is associated with a 40% increased risk of type 2 diabetes in the United States, and the risk is higher for women than for men (Agardh et al 2011). Thus female caregivers likely experience a greater disparity.

Low-income and no income female caregivers have reported experiencing more chronic medical conditions and functional limitations compared to the general population (Weinreb et al 1998). These women reported a variety of barriers to medical care including limited access to transportation, childcare, problems getting to an appointment, or having to wait too long for an appointment. Food insecurity, an indicator of material hardship prevalent in these women, is defined as "whenever the availability of nutritionally adequate and safe foods or the ability to acquire foods in socially acceptable ways is limited or uncertain. Food insecurity has been linked to a number of chronic

diseases such as obesity, hypertension, dyslipidemia, ischemic heart disease, and type 2 diabetes (Malnick and Knobler 2006). Not only are female caregivers responsible for meeting their own needs and managing their own health, but they are also responsible for taking care of the needs of dependent children or grandchildren. This may be especially difficult to juggle if the caregiver suffers from chronic medical conditions, such as type 2 diabetes.

There are various factors that may influence the management of type 2 diabetes that are specific to low-income female caregivers. Diet quality is particularly important in the management of type 2 diabetes (ADA 2013). Studies have shown that food insecurity and poverty are associated with poor diet quality (Drewnowski 2009). Additionally, poor diet quality may lead to poor diabetes management and blood glucose control (Seligman et al 2012). Low-income female caregivers may have fewer resources to provide healthy foods for them and their families.

Caregiving may also influence mental health status through increased stress and depression (Penckofer et al 2007). Specifically, parenting burden can negatively impact the health of mothers with diabetes by decreasing perception of general health and psychological well-being postpartum (Dalfrà et al 2012). Caregivers, especially caregiving grandmothers, may take on multiple roles, thus becoming a "multicaregiver" (Samuel-Hodge et al 2000). The responsibility to fill multiple roles and meet the needs of family members may act as an obstacle to successful diabetes management. Furthermore, stress, depression, and anxiety are associated with poorer diabetes management and glycemic control (McKellar et al 2004; Anderson et al 2002). Stress and depression due to caregiving could further exacerbate poor diabetes management and glycemic control.

Emotional distress specifically related to the diabetes regimen affects the relationship between food insecurity and diabetes management (Seligman et al 2012). Diabetes-related emotional distress is the feeling of being overwhelmed by the diabetes regimen (Polonsky et al 1995). In other words, it is emotional distress associated with maintaining the recommended diabetic diet, physical activity, blood glucose testing, and medication compliance. Women are at increased risk of greater diabetes-related distress over time, as are those with poor diet and physical activity (Fisher et al 2009). Thus it is likely that female caregivers experience increased diabetes-related emotional distress in addition to general psychological stress.

Little research has been conducted to assess the management of chronic disease in low-income female caregivers, primarily mothers and grandmothers. Previous studies are predominately qualitative and assess only one or two of the potentially influencing factors of caregivers experiencing food insecurity and diabetes management. Moreover, there is little information on the diet quality of diabetic, low-income female caregivers as it compares to recommendations for diabetes management. Such information is critical for designing nutrition interventions for this population.

The overall goal of this feasibility study is to understand the status of and factors associated with diabetes management in low-income female caregivers, while exploring and establishing a new partnership with programs and organizations to reach the target population.

CHAPTER 2

LITERATURE REVIEW

Low-income female caregivers in the United States

There are a number of different types of households in which a female caregiver may reside. These family households may be headed by married couples or single females. For the purposes of this study we define "caregiver" as one who is responsible for attending to the needs of a child or adult child. Although a female caregiver may be the mother, grandmother, aunt, cousin, or some other relationship to the children in the household, we limit our review of the literature to primarily mothers and grandmothers. Single mother-headed households with children make up 9.2% of all households in the U.S. (US Census Bureau 2014a). Some minority groups are disproportionately affected where 21.2% of African American and 14.8% of Hispanic households are headed by single mothers compared to 6.2% of white, non-Hispanic. Households may also be multigenerational in which grandparents are coresidents of their grandchildren. Four percent of people over the age of 30 live with their grandchildren, majority of which are women (Ellis and Simmons 2014). Of those living with grandchildren, 39% claimed to be primary caregivers for their grandchildren. Similar to single mother-headed households, caregiving coresident grandparents are more prevalent in minority communities, particularly African Americans.

In 2014, families made up of single female-headed households showed a higher poverty rate at 30.6% compared to 5.8% of married couple households, 15.9% for male-

headed households, and 14.5% for all people in the U.S. (DeNavas-Walt and Proctor 2014). In 2012, the most recent report of coresident households showed that grandparent-headed coresident households also had a higher rate of poverty at 19.8%. (Ellis and Simmons 2014). For grandmother-headed, no parent households, the poverty rate is even higher at 44.2%. This increase in poverty may be a result of economic distress that has resulted in an increase in multi-generational living arrangements. Additionally, in 2013, 65.7% of single female-headed households received public assistance compared to 33.5% of all U.S. households (U.S. Census Bureau 2014b). Moreover, of all coresident households in 2012, 44% of parent-maintained homes and 55% of grandparent-maintained homes received public assistance compared to 36% of households without coresident grandparents (Ellis and Simmons 2014). Therefore, women with caregiving responsibilities, regardless of age, disproportionately experience poverty.

In regard to health, low-income groups experience higher prevalence of chronic disease than higher income groups (CDC 2015). More specifically, low-income is associated with a 40% increased risk of type 2 diabetes in the United States, and the risk is higher for women than for men (Agardh et al 2011). Burden of chronic disease is experienced both physically and mentally. Reports of fair or poor self-reported health, physically unhealthy days, or mentally unhealthy days are higher among women, minority race/ethnic groups, individuals with lower household incomes, and individuals with chronic disease (Zack 2013). Both sheltered homeless and low-income housed women with dependent children have reported greater prevalence of chronic medical conditions and functioning limitations compared to the general population (Weinreb et al 1998). Additionally, they have reported barriers to medical care including lack of

transportation, lack of childcare, problems getting to an appointment, or waiting too long for an appointment. Bachman et al (2005) reported that custodial grandmothers experienced similar material hardship to that of mothers and more self-reported physical limitations and chronic disabilities. Thus, there is an increased vulnerability of low-income female caregivers to health-related issues that manifests itself both mentally and physically.

Food insecurity in low-income female caregivers

Food insecurity is defined as "whenever the availability of nutritionally adequate and safe foods or the ability to acquire foods in socially acceptable ways is limited or uncertain" (Anderson 1990). In the U.S., 14.3% of households were categorized as food-insecure in 2013 (Coleman-Jensen et al 2014b). Food insecurity classified based on experience of problems with food access, diet quality, and diet quantity. Families with lower incomes have a higher risk of food insecurity, where 40.3% of U.S. households with children, with incomes below 185% of the poverty level classify as being food-insecure (Coleman-Jensen et al 2014b).

For households headed by a single woman, however, rates for food insecurity continue to be higher than the national average (34.4% vs 14.3%) (Coleman-Jensen et al 2014b). "Other households with children," defined as household with children in complex living arrangements such as with relatives, have a 30.7% prevalence of food insecurity. These households may include grandparent-headed households or households in which the grandparent may take some or all responsibility in child caregiving. Grandparents over the age of 40 with grandchildren present are more likely to experience food insecurity compared to seniors without grandchildren present (Ziliak and Gundersen

2011). A study comparing caregiving grandparents to non-caregiving grandparents found that grandparents who served as caregivers were more likely to be single women, African American, and low-income than grandparents without caregiving responsibilities (Fuller-Thompson and Minkler 1997). These demographics may put caregiving grandmothers at risk of food insecurity. Baker and Mutchler et al (2010) found that food security status was consistent with poverty status and explained by demographics in caregiving grandparents. Thus, caregiving grandmothers may have a similar risk of food insecurity as mothers.

Food assistance programs for low-income female caregivers

Many households with limited resources struggle to make ends meet and turn to federal food and nutrition assistance programs to help meet their food needs. The Special Supplemental Nutrition Assistance Program for Women, Infants, and Children (WIC) is a federally funded program that targets low-income mothers who are pregnant, breastfeeding or nonbreastfeeding postpartum, infants, and children under the age of 5 (Coleman-Jensen et al 2014b). The WIC program provides vouchers for approved foods as well as nutrition education and health care referrals. The Supplemental Nutrition Assistance Program (SNAP), formerly known as the Food Stamp Program, also provides monthly benefits for food purchasing for low-income families and individuals based on household income. Although this program aims to alleviate food insecurity in a vulnerable, low-income population, it is likely that program participants seek out the program due to more severe levels of food insecurity. According to the USDA Economic Research Service, 54.2% of SNAP participants and 42.3% of WIC participants are food-insecure.

Food insecurity and health status

Those who experience food insecurity are often involved in compensatory behaviors in order to prevent hunger (Seligman et al 2010b). Such behaviors often include purchase of low-cost, energy-dense foods that are high in fat and added sugars (Drewnowski and Spector 2004). When individuals are striving to stretch their food dollar, they may seek energy-dense foods in order to save money. These energy-dense foods are often more palatable but less satiating, which may lead to overconsumption. Overconsumption may also occur due to the cyclical nature of food scarcity (Seligman et al 2010b). When food is limited, food-insecure individuals may restrict consumption, however, in times of food adequacy, they may overconsume. In light of poorer diet quality associated with food insecurity, Seligman et al (2010b) constructed a conceptual model portraying the link between potential inability to purchase high quality, healthy foods and the high incidence of obesity and chronic disease in food-insecure populations.

Food insecurity has been associated with poorer self-rated overall health status and physical and mental health scores (Stuff et al 2004). Specifically, obesity has been linked to food insecurity in a number of populations. Studies in children show conflicting evidence (Alaimo et al 2001; Casey et al 2006; Gunderson et al 2009; Lohman et al 2009; Martin and Ferris 2007), as have studies in men (Hanson et al 2007; Martin and Ferris 2007; Townsend et al 2001). In women, however, a strong, consistent association has been found between food insecurity and obesity (Adams et al 2003; Gooding et al 2012; Hanson et al 2007; Martin and Ferris 2007; Townsend et al 2001). Similarly, the Institute of Medicine (2011) published a report citing that compared to their food-secure counterpart, children in food-insecure households were probably not more likely to be

obese. For adults, food-insecure women, but not men, were more likely to be obese. The report also noted the importance of accounting for socioeconomic status because obesity and poverty are associated, and poverty and food insecurity likely coexist. An association has also been shown in older women. One study looking at baby boomers and older adults showed similar findings in which food-insecurity lead to a 1.4 times higher likelihood of a higher body mass index in women (Ahn et al 2014). It is possible, therefore, that grandmothers who likely fall into older age groups also experience such risks.

There is little research about the effects of food insecurity on the health of mothers and caregiving grandmothers. It has been reported, however, that high demands of child care and scarce resources can lead to a decline in health of the grandmother (Hughes et al 2007). Grandmothers from minority groups also experience higher rates of obesity. African American caregiving grandmothers, for example, were found to have higher rates of overweight and obesity than the national average for African American women over age 20 (Kelly et al 2013). Although food insecurity was not assessed in these women, the majority were low-income and at higher risk of food insecurity. Consequently, food insecurity may have played a role in obesity prevalence.

It is well accepted that obesity is directly associated with many chronic diseases including diabetes mellitus, hypertension, dyslipidemia, and ischemic heart disease (Malnick and Knobler 2006). Weak associations have also been found linking higher rates of dyslipidemia to food insecurity in women, but not in men (Tayie and Zizza 2009). Additionally, a recent study using NHANES data found food security status to be significantly associated with a predicted 10-year cardiovascular disease risk of greater

than 20% for adults aged 30 to 59 years (Ford 2013). Previous studies have also shown that food-insecure populations have a higher prevalence of other chronic disease such as metabolic syndrome, hypertension, and diabetes (Parker et al 2010; Seligman et al 2010a).

Food insecurity and diabetes

Diabetes in food-insecure populations is a relatively new area of research. About 9% of all Americans have diabetes (CDC 2014). For women over the age of 20, that prevalence is higher at 11.2%. Other risk factors include older age, obesity, and race/ethnicity such as African Americans, Hispanics/Latinos, and American Indian. Diabetes also disproportionately affects those who are food-insecure. Diabetes prevalence is significantly higher in food-insecure populations compared to food-secure populations (16.7% vs. 11.7%, Seligman et al 2007). Similarly, a study in Canada found that 9.3% of diabetics in their study sample were food insecure compared to 6.8% of non-diabetics (Gucciardi et al 2009). This study also showed an even bigger disparity in women between ages 12 and 45 in which 25% of women with diabetes were food insecure compared to 9.5% of women without diabetes. In Latinas, women with very low food security were 3.3 times more likely to have type 2 diabetes than those with food security or low food security (Fitzgerald et al 2011). Thus, low-income female caregivers with food insecurity may be at higher risk for type 2 diabetes.

Food insecurity and diabetes management

Part of maintaining good health status for those with diabetes involves disease management. Recommendations for optimal management of type 2 diabetes includes a healthy diet, carbohydrate monitoring, at least 150 min/wk of physical activity, blood

glucose monitoring several times a day, and potentially pharmacotherapy (ADA 2013). Food insecurity, however, has been associated with poorer diabetes management as indicated by poorer glycemic control (Lyles et al 2013). Seligman et al (2012) found that, in patients from safety net clinics, with type 2 diabetes, poor glycemic control (defined as hemoglobin A1c (HbA1c) $\geq 8.5\%$) was more prevalent in food-insecure patients than food-secure patients. Food insecurity also mediates about one third of the association between housing instability and diabetes self-efficacy, an important influence on successful self-management (Vijayaraghavan et al 2011). According to the conceptual model developed by Seligman et al (2010b), poor diabetes self-management of food insecure individuals is influenced by the reduced ability to afford a diabetic diet, depression, and the competing costs of medications and health care. Reduced food security and socioeconomic status have been linked to decreased health status and health-related quality of life in individuals with type 2 diabetes (Maddigan et al 2006).

Other factors affecting diabetes management in low-income female caregivers

In regards to low-income mothers, there are other factors that could influence diabetes management that are specific to female caregiver. Seligman et al (2012) assessed potential mediators between food insecurity and poor glycemic control and found difficulty following a diabetic diet and emotional distress mediated the association. Poor diet quality, general psychological health, and diabetes-related distress all have the potential to be elevated and influence food insecurity and diabetes management in low-income mothers.

Diet quality

Poor diet quality is common in low-income households because unhealthy, energy-dense foods tend to be less expensive, whereas healthier, nutrient-dense foods are often more expensive (Drewnowski 2009). Such unhealthy diets, which are higher in fats, added sugars, and refined grains are not reflective of diets recommended for diabetics. The American Diabetes Association (ADA) (2013) recommends a diet of whole grains, fruits, vegetables, legumes and low fat dairy. Individuals with diabetes should also limit and reduce intake of saturated fats and cholesterol. One qualitative study assessed challenges to healthy eating in a low-income minority sample of individuals with diabetes (Breland et al 2013). Commonly reported challenges to healthy eating included limited access, money, transportation, and time for purchase of healthy food items, while less healthy were more convenient foods. Reports of poor and nonspecific medical advice from clinicians, feelings of potential isolation from culture and family with dietary change, and stress related to racial discrimination and poverty were also major themes expressed by study participants.

Differences in dietary behavior between food-secure and food-insecure are reflected in the several studies. Mello and colleagues (2010) found increased consumption of fruit juice and lower prevalence of fat-lowering dietary behaviors. These behaviors may be due to an inability to afford healthier options or nutrition knowledge deficit. Additionally, a Canadian study of low-income mothers found that dietary intake is sensitive to income depletion over the course of one month (Tarasuk et al 2007). For moderate or severe food insecurity there was a significant decline in energy intake, carbohydrate, vitamin B-6, fruits and vegetable intake. Diet quality has also been

assessed in Alabama food pantry participants from which a majority of participants were food-insecure and the majority reported no fruit, limited vegetable, and no legume intake (Duffy et al 2009). Similarly, in a sample of Connecticut food pantry participants, those who were food-secure were 2.3 times more likely to consume fruits, vegetables, and fiber than those who were food-insecure (Robaina and Martin 2013).

Caregiving Burden

In food-insecure women, motherhood is associated with a higher prevalence of obesity, a risk factor for diabetes, compared to childfree women (Martin and Lippert 2012). Such an association is suggested to be partially due to parenting responsibilities involved with motherhood and is not diminished with the receipt of WIC or other food assistance. Parenting burden negatively impacts the health of mothers with diabetes, as well, by decreasing perception of general health and psychological well-being postpartum (Dalfrà et al 2012). In a qualitative study by Dammann and Smith (2009), low-income mothers reported increased stress associated with caring for their families, as well as the inability to provide healthy foods due to financial strain.

The limited research on how caregiving influences the success of diabetes management has been primarily conducted using qualitative research methods. One study examined the role of children in a parent's diabetes management (Laroche et al 2009). While the study found some benefits of a child's role in the parent's diabetes management, parents reported being tempted to stray from their prescribed diets because their children's diets included foods that the parents were trying to limit or avoid. Although the focus was on children aged 10-17, findings may still reflect the influence of younger children on parental diabetes management. A second qualitative study

interviewed African American women with type 2 diabetes, mostly aged >55 years (Samuel-Hodge et al 2000). These women thematically reported that added responsibility for providing aid to family members increased stress and acted as a barrier to successful diabetes self-management. These results show that this burden of caregiving continues through later years of life.

The burden of caregiving and its effect on diabetes management carries over to grandmothers as well. Caregiving grandmothers have the unique role as "multicaregivers." These women often fill multiple roles of caregiving to adult children, grandchildren, and homebound parents (Carter-Edwards et al 2004; Samuel-Hodge et al 2000). Caregiving grandmothers have reported difficulty and stress in prioritizing their own health over others. It may be that caregiving grandmothers put their adult children's and grandchildren's needs before their own due to the grandmothers' sense of responsibility towards them. Another study by Cathron et al (2010) assessed African American caregiving grandmothers. The study found that these grandmothers had more difficulty adhering to a healthy diet and performing self-monitored blood glucose tests after the initiation of caregiving. Overall, these grandmothers performed fewer self-monitoring blood glucose tests and eye exams compared to non-caregiving grandmothers. These same researchers investigated the reasoning behind this poor diabetes management by interviewing African American caregiving grandmothers (Cathron et al 2014). The grandmothers reported that fatigue and exhaustion from physical caregiving acted as a barrier to good diabetes management. They also reported strain from financial caregiving was a barrier to healthy food choices and purchase of medical supplies. A study by Kicklighter et al (2007) found that barriers to good nutrition and exercise in grandparents

raising grandchildren included cost, childcare responsibilities, and having to consider grandchildren's food preferences and tastes. Strains on caregiving due to food insecurity could intensify such negative health impacts on mothers with diabetes.

Psychological influence of caregiving goes beyond stress and financial strain. Depression and anxiety have been linked to negative diabetes outcomes as a result of poorer adherence to self-management activities (McKellar et al 2004; Anderson et al 2002). Penckofer et al (2007) assessed feelings of depression, anxiety, and anger experienced by women with type 2 diabetes and found that these feelings were primarily due to having diabetes and multiple responsibilities as caregivers. Similarly, in regard to food security status, it has been found that diabetic individuals who were food-insecure more commonly perceived both mental health and stress as "poor to fair" compared to those who were food-secure (Gucciardi et al 2009). The additional stress of managing food insecurity could influence the success of diabetes self-management in female caregivers who are already at risk for poorer mental health. Thus, this merits further exploration.

Diabetes-related emotional distress

In addition to general emotional stress from outside sources, diabetes-related emotional distress (DD), defined as feeling overwhelmed by the diabetes regimen, is shown to independently and negatively contribute to diabetes self-care practices and glycemic control (Polonsky et al 1995). In Polosnky's study, DD included categories related to feelings of anger, interpersonal distress, and frustration with aspects of the diabetes regimen. In relation to diabetes self-management, decreased DD is associated with improved glycemic control and self-care behaviors such as exercise, diet, and foot

care (Fisher et al 2010; McEwen et al 2010). Individuals with type 2 diabetes have also reported feelings of guilt pertaining to poor self-care and living with diabetes (Miller 2011). The mode of treatment may also influence to degree of diabetes-related distress in those with type 2 diabetes, with potential for greater distress for insulin-treated individuals (Delahanty et al 2007). This influence of treatment is also potentially due to disease severity and self-care burden. Being a woman, younger, experiencing more negative life events and non-disease-related chronic stress, low physical activity, and poor diet is shown to increase risk of higher diabetes distress over time (Fisher et al 2009). Thus, food insecurity and caregiving could also add to the emotional stress of maintaining the diabetes regimen. The study also showed that with more negative life events, the odds of higher DD over time increased in those with high HbA1c. Seligman et al (2012) conducted a more direct assessment of food insecurity, diabetes-related distress, and diabetes management. Researchers revealed DD as a possible mediator between food insecurity and poor glycemic control in a safety-net sample, with DD mediating 34% of the effect. Thus, diabetes-related distress is worth exploration in female caregivers with heavy responsibility to take care of others.

Preliminary studies

Food insecurity and diabetes management

Seligman et al (2012) examined the association between food security status and glycemic control. The researchers administered a cross-sectional survey and reviewed medical charts in a convenience sample of 711 patients with type 2 diabetes from multiple safety net clinics. To assess food security status they utilized the U.S. Household Food Security Survey Module, which has been widely used and accepted as a valid

measure of food security in the U.S. As the primary outcome, HbA1c values were obtained from patient medical charts. In an attempt to explain how food insecurity may affect glycemic control, three mediators were examined including difficulty following a diabetic diet, self-efficacy, and emotional distress. The researchers found that in low-income diabetic patients of safety net clinics, more food-insecure individuals had poor glycemic control (defined as $HbA_{1c} \geq 8.5\%$) than did food-secure individuals. Difficulty following a diabetic diet and emotional distress mediated food insecurity and poor glycemic control. Several of the approaches from Seligman et al (2012) were used in this research study.

Caregiving burden and diabetes management

Dammann and Smith (2009) investigated the factors affecting food choices and health beliefs in low-income women given their weight status and income. This qualitative study sampled 92 low-income women with at least one child in the household. Participant reported insufficient food stamps, food price, and limited food storage as barriers to food choices. Researchers also found that participants prioritized their children to receive food first before they ate, and that healthy diet was not affordable to them despite having health conditions. Ultimately, it was concluded that increased stress in low-income mothers is associated with caring for their families, as well as the inability to provide healthy foods due to financial strain.

Carthron et al (2014) conducted a qualitative, longitudinal study to the effect of multi-caregiving roles of African American grandmothers on type 2 diabetes management. The sample consisted of 6 African American women with type 2 diabetes from a Grandparent Center. Five interview sessions were held over 18 months. Several

themes emerged from the interviews. Participants reported that physical caregiving led to increased fatigue and exhaustion that interfered with checking blood sugar or exercising. These grandmothers also reported that financial caregiving caused financial strain that led to difficulty in purchasing diabetes testing supplies, medication, and healthy foods. Other themes included the roles as spiritual caregivers and community caregivers, which also presented some adaptive challenges to diabetes management. These studies were used to support the focus of this current research study on low-income female caregivers.

Challenges in conducting research with hard-to-reach populations

A systematic review of literature assessed the barriers to targeting socioeconomically disadvantaged groups for health and medical research (Bonevski et al 2014). Barriers to sampling included difficulty reaching the target group and low-prevalence of the group in the population. One suggested strategy was the collaboration with community organizations that has access to the target population.

Barriers to recruitment of socioeconomically disadvantaged groups included mistrust in the research/researchers, fear of authority, perceived harms of research, and perception of no personal benefit (Bonevski et al 2014). Other barriers to recruitment include rigid, exclusive eligibility criteria, participant lack of understanding, cultural-related issues, low response rate, and restrictive gatekeepers to participants. In particular, strategies to rigid exclusivity criteria include flexible eligibility criteria and financial incentives for support staff. Strategies to overcome low-response rates may include multiple contact attempts, contacting through health services, outreach/home visits, incentives, shorter surveys, and assistance with transportation or childcare.

Bonevski et al's (2014) review reported some barriers to data collection in socially disadvantaged groups including language and low literacy, which may prevent the use of self-administered surveys. Suggested solutions to improve data collection include offering measures in other languages, avoiding self-administered questionnaires, and using short surveys. This systematic review was used as a basis of carefully designing this study in an effort to eliminate potential barriers.

Rationale, specific aims, and hypothesis

Households with children or headed by a single woman have greater prevalence of food insecurity than the national average (19.5% and 34.4% vs 14.3%, USDA ERS, 2014). Low-income mothers report emotional and financial challenges to providing healthy foods for their families with limited financial resources, which in turn minimizes priority of health concerns (Dammann et al 2009). Caregiving grandmothers have also reported cost and childcare responsibilities as a barrier to good nutrition and exercise (Kicklighter et al 2007). In a population with incomes of ≤ 300% of the federal poverty level, diabetes is more prevalent in food insecure populations (16.7%) compared to food secure populations (11.7%) (Seligman et al 2007). Food insecurity is also linked to poor diabetes management for low-income populations (Seligman et al 2012). Very little research has been published to assess factors associated with diabetes management. Targeting low-income female caregivers, an understudied population, will help expand understanding in this area of research. This study serves as a pilot study and stepping stone to fill in the gaps about our knowledge of diabetes management in low-income populations through the use of a sample of diabetic women enrolled for services at a safety net clinic.

The overall goal of this research is to understand the status of and factors associated with diabetes management in low-income female caregivers with diabetes enrolled for medical services at Athens Nurses Clinic in Athens, GA. This study is a pilot study, which aims to test the feasibility of using the proposed methods and measures among female caregivers with diabetes. The research question is, "what factors are associated with poor diabetes management in low-income female caregivers with diabetes?" The overall hypothesis is that factors associated with poor diabetes management in low-income female caregivers with diabetes include food insecurity, diet quality, caregiving burden, psychological health, and diabetes-related emotional stress. The first specific aim is to describe the self-management behaviors associated with glycemic control in female caregivers with diabetes. The second specific aim is to compare characteristics of low-income female caregivers with poor vs good glycemic control in terms of food insecurity, diet quality, caregiving burden, general psychological health, and diabetes-related emotional distress, as is related to diabetes management. The third aim of this study is to explore the process and feasibility of establishing a new partnership with a non-profit community organization such as Athens Nurses Clinic to conduct the proposed study.

CHAPTER 3

METHODS

The present study involves development of a new partnership with a community organization providing services to low-income female caregivers as well as the conduct of both primary and secondary data collection and analysis. All methods and procedures were approved by the University of Georgia Institutional Review Board (IRB) before any procedures with human subjects were initiated (IRB# 00001139).

Study design

This study used a cross-sectional study design that included hour-long, one-time, interviewer-administered surveys and review of participant medical records in order to collect the data to examine factors influencing diabetes management in low-income female caregivers.

Study sample

The inclusion criteria for this study included: (a) low-income woman of all races and ethnicities, (b) at least one financial dependent, (c) at least 18 years of age, (d) current diagnosis of type 2 diabetes, (e) patient at Athens Nurses Clinic in Athens, GA, and (f) not currently pregnant.

Recruitment

Beginning in October 2013, Rachel Laudel made initial attempts to build partnership with East Athens WIC clinic and then Mercy Health Center in Athens, GA with the intended eligibility pool narrowed to low-income mothers only. The East Athens

WIC Clinic serves pregnant, postpartum, and breastfeeding women and children up to the age of five who are at or below the 185% of the federal poverty level or on Medicaid and who are at risk of nutritional deficiencies. Participants of the program receive free services including nutrition assessment, health screenings, medical history, nutrition education, breastfeeding support, and health care referrals. The WIC clinic also provides vouchers for nutritious foods. WIC was initially chosen for this study due to the program eligibility criteria of being a mother with low household income. The WIC sample was convenient and narrowed, particularly well matched for a focus on assessment of caregiving burden. While East Athens WIC Clinic found interest, final authority concluded that the district was unable to facilitate a partnership for this study due to the clinic's focus on newly implemented programs and maintenance of high caseloads.

Mercy Health Center was a second community organization that was initially targeted to build a partnership. Mercy Health Center is a faith-based safety net clinic for uninsured, low-income individuals and provides free medical, dental, and specialty health services. Nutrition counseling is also offered as well as referrals to physical therapy. Service providers at Mercy Health Center work on a primarily volunteer basis with the exception of some administrative staff. The assistant director of Mercy Health Center was contacted to inquire about demographics of their patient population and interest in hosting this study. While Mercy Health Center expressed interest in a partnership, it was determined that clinic patients with type 2 diabetes were primarily middle aged or older adults and likely without children in the home. Due to the reportedly limited pool of eligible participants, Mercy Health Center was unable to assist with this study.

Starting in August 2014, researchers contacted the executive director and the volunteer and patient coordinator at Athens Nurses Clinic in Athens, GA to describe the study and for request of partnership with the University of Georgia for the study in regard to patient recruitment, use of medical records, and facility use. Athens Nurses Clinic is a non-profit, safety net clinic that provides medical and dental services for acute and chronic conditions to uninsured low-income individuals around Athens-Clarke County, GA. These services include acute care, chronic disease management, laboratory services and blood work, health education counseling, women's health, dental, and prescription assistance. The clinic is run by nurses, staff, and volunteers. The executive director and volunteer and patient coordinator agreed to assist with this study and, upon agreement, completed IRB CITI training. A Spanish interpreter affiliated with the clinic was also trained to assist with Spanish-speaking participants.

Researchers provided the trained clinic collaborators with a list of eligibility criteria. The trained clinic collaborators screened patient medical records for eligibility. Initial eligibility criteria was narrowed to mothers, and ultimately broadened to women with financial dependents due to the initially limited pool of eligible participants. Clinic collaborators created a patient contact list for those screened eligible. A partial waiver of HIPPA authorization was granted allowing trained clinic collaborators to share the eligible participant contact list with the UGA research team.

The research team used direct recruitment methods via telephone calls using the contact information provided by the trained clinic collaborators and a recruitment script found in **Appendix A**. The researcher explained the purpose of the study and confirmed eligibility. The eligible participants were informed that the visit would take about an hour

to complete all questionnaires. The researcher then scheduled a time for the eligible participant to come into the clinic based on patient availability. Indirect recruitment methods were also later used through posting flyers, found in **Appendix B**, throughout the clinic and mailing flyers to the homes of potentially eligible participants.

Upon the participant's arrival to the clinic, the participant reviewed and signed an informed consent form and a HIPPA authorization form, shown in **Appendix C** and **D**, respectively. The clinic collaborators or UGA research team member was present to answer any questions from the participants. Researchers were provided a script for obtaining consent, shown in **Appendix E** and administering the questionnaires. A trained Spanish interpreter was used in the case of a Spanish-speaking patient.

Medical chart review

Characteristics of study sample

A review of participant medical charts was conducted upon the authorization of the participant. Secondary data retrieved from medical records included participants' sociodemographic and medical information including age, race/ethnicity, family size, head of household status, household income, health insurance, food assistance participation, medical diagnoses, medication use, and HbA1c. As a subset of documented medical conditions, diet-related chronic conditions were recorded, focusing on diabetes, obesity, hypertension, and dylipidemia. Body Mass Index (BMI) data, as measured in kg/m^2, was collected from the medical chart and verified against height and weight data. The 3 most recent HbA1c values documented in participant medical records were collected and intervals between documented HbA1c values were also recorded. The ADA recommends that individuals with type 2 diabetes should have a goal to keep HbA1c of

<7% (ADA 2013). Due to consistency between each participant's last 3 documented values, participants categorized based off glycemic control (GC) using average HbA1c values with HbA1c <7% (good GC) versus HbA1c ≥7% (poor GC).

In-person interviews

After consent was obtained, participants were then interviewed through researcher-administered questionnaires in a private room of the clinic to ensure discretion. The interview session last approximately one hour. Questionnaires, shown in **Appendix F**, assessed multiple areas related to the following domains assessed during the interview: diabetes self-management, food security status, general psychological health, diabetes-related distress, and additional information regarding the participant and her dependents.

Diabetes self-management assessment

Diabetes self-management was assessed through administration of the Summary of Diabetes Self-Care Activities (SDSCA) questionnaire (Toobert et al 2000). This 11-item questionnaire assessed self-care components of general and specific healthy eating, physical activity, blood glucose testing, and foot care.

Previous studies have used this assessment. Management in low-income and underserved populations has been previously assessed using the SDSCA. A study by Greene et al (2005) utilized the SDSCA to assess diabetes self-management in a high minority, low-income sample and found better provider self-management support associated with higher self-management performance. Another study using a similar population found consistency throughout all domains of the SDSCA for the relationship between diabetes self-management and self-efficacy (Sarkar et al 2006). The SDSCA

was, therefore chosen as a tool to assess diabetes self-management in a sample of low-income female caregivers. To analyze this data, the mean of each category (diet, exercise, blood glucose testing, and foot care) was calculated. Values are intended to indicate relative adherence such that higher values within each category indicate better management for that activity.

Dependents

Additional information was collected by asking questions concerning number of dependents, age of dependents, and relationship to dependents. Contribution of dependent to household income was also assessed.

Food security assessment

Food security status was measured using the US Household Food Security Survey Module (Bickel et al 2000). This survey module includes questions evaluating an individual's ability to afford balanced meals and her experience of having to reduce diet quality or quantity. It has been widely used and accepted as a valid measure of food security in the U.S. The long form of the survey has been used in a sample of low-income patients with diabetes, a similar population to our study (Seligman et al 2012). A six-item short form of this questionnaire, which was validated against the 18-item form by Blumberg et al (1999), was used to reduce respondent burden and to briefly assess food security status in individuals with diabetes. Food security status can be assigned by 2 categories, with scores 0-1 considered "food-secure" and scores 2-6 considered "food-insecure." Status can also be assigned by 4 categories. Food security indicates no problems or anxiety about consistent, adequate food access (Coleman-Jensen et al 2014a; Wunderlich and Norwood 2006). Marginal food security indicates problems at time for

accessing adequate food, but quality, amount, and variety were not significantly compromised. Low food security indicates households that have food access problems and reduced diet quality, but little or no reduction in food intake. Very low food security indicates households that have reduced intake and disrupted eating patterns due to lack of money and food resources. For this study, food security status was categorized with the score 0 as high food security, 1 as marginal food security, 2-4 as low food security, and 5-6 as very low food security (Blumberg et al 1999).

Psychological factors: general mental health assessment

General mental health was evaluated as a factor associated with diabetes self-management due to the negative effects on mental health women may experience due to the burden of caregiving. The Depression Anxiety Stress Scale (DASS-21) was used to measure psychological well-being. This 21-item scale has been validated against the longer 42-item version (Antony et al 1998). The DASS-21 can be grouped into three scales: depression, anxiety, and stress and has been shortened to eliminate respondent burden. Specifically, the depression scale measures symptoms of sadness or worthlessness. The measure of anxiety includes a component of fear and hyperarousal. The stress component indicates high levels of tension, irritability, and overreaction to stressful situations. This scale has been used previously to assess psychological well-being in diabetes self-management intervention study (Clarke et al 2014). This scale was used to measure general psychological health in this current study. Within the questionnaire, there are 7 questions per category (depression, anxiety, and stress). Values for depression, anxiety, and stress were determined by summing the scores for each

corresponding question. Higher values in each category indicate higher levels of depression, anxiety, or stress.

Psychological factors: diabetes-related emotional distress assessment

Diabetes-related emotional distress was assessed using the Problem Areas in Diabetes Scale (PAID-5). This five-item scale is the short form of the 20-item PAID questionnaire (Polonsky et al 1995). The PAID has been found to be a unique contributor to diabetes management and had been associated with hemoglobin A1c, an indicator of blood glucose control. The PAID-5 questionnaire evaluates for fear, depressed mood, demands of living with diabetes, and concerns about the future (McGuire et al. 2009). It has been previously used as a part of a large, multi-national survey administered to people with diabetes, family members, and health care professionals (Peyrot et al 2013). Thus, PAID-5 was, therefore used in this study to assess diabetes-related distress. The questionnaire was scored though summation of each question's individual score. Overall scores of ≥ 8 may indicate diabetes-related emotional distress.

Dietary intake assessment

After completing the questionnaires, participants were asked to complete a 24-hour dietary recall on a laptop provided. To assess dietary intake and diet quality the Automated Self-Administered 24-Hour Dietary Recall (ASA24), developed by the National Cancer Institute for use in large research studies, is modeled from the Automated Multi Pass Methods (AMPM) (Subar et al 2012). The ASA24 is a web-based dietary recall that includes both a respondent and a researcher website and assumes Internet and computer access. To eliminate barriers to computer and Internet access,

researchers provided a computer and guided participants through the diet recall at the clinic.

As a fully automated tool, the ASA24 is a cost-effective tool that minimizes reliance on trained interviewers. The ASA24 aims to reduce cost and data collection burden by making it easier for respondents to self-administer the recalls. The research team assisted participants in completing the diet recall, however, to expedite website navigation and to answer any questions from participants. Details of food preparation and portion size are incorporated, and images are provided to aid in comprehension of portion size for better accuracy.

For the purpose of this study, energy intake, carbohydrate, total fat, and saturated fat distribution, and intake of whole grains, fruits, and vegetables were estimated and analyzed. These variables were chosen in order to compare participants' reported diets to ADA nutrition recommendations (Evert et al 2013). There are no set macronutrient distribution recommendations for diabetes, however, current diabetes recommendations are in line with that of the general population: carbohydrate 45-65%, total fat 20-35%, and saturated fat <10% of total energy needs. Recommendations also include 25 g of dietary fiber, and fruits, vegetables, and whole grains as recommended for the general population.

Energy needs for each participant were determined using the Mifflin-St. Jeor formula, based off of actual body weight, height, sex, and age, as recommended by the Academy of Nutrition and Dietetics' evidence-based recommendations (AND 2014). Participant energy needs were calculated based on weight maintenance rather than weight

loss, because weight loss is not a focus of this study. Latest height and weight data from participant medical records were used to calculate energy needs.

Participant incentives

Upon completion of the research study, participants received a $10 grocery store gift card along with a diabetic-friendly cookbook.

Data analysis

For the purpose of this study and small sample size, mostly descriptive statistics were used to summarize the participant characteristics and diabetes self-management information collected from both in-person interviews and medical chart reviews. The ADA recommends that individuals with type 2 diabetes should have a goal to keep HbA1c of <7% (ADA 2013). Due to consistency between each participant's last 3 documented values, HbA1c values were averaged for each participant. The sample was dichotomized based off glycemic control (GC) using average HbA1c values with HbA1c <7% (good GC) versus HbA1c ≥7% (poor GC). Mean, standard deviation, median, minimum, maximum, and percentages for the total sample and by GC groups were calculated using Microsoft Excel.

CHAPTER 4

RESULTS

Recruitment

After screening patients from Athens Nurses Clinic, 22 women were found to meet eligibility criteria. **Table 1** describes the results of recruitment for this study. Through telephone recruitment, UGA researchers made up to 4 attempts to contact participants. Of the 22 eligible participants, one (4.5%) woman did not have transportation, 3 women (13.6%) had disconnected phones, 8 women (36.4%) could not be contacted and messages were left, one woman (4.5%) was recruited but did not show up, and 5 women (22.7%) requested researchers to call them back at a later time, but could not be reached in subsequent attempts. Flyers were then mailed out to the homes of eligible participants as an indirect method of recruitment, from which one participant was recruited. A total of 4 (18.2%) participants took part in this study. One participant (4.6%) was recruited through mailed flyers, and 3 participants (13.6%) were recruited through telephone calls.

Characteristics of study sample

All 4 participants were females and receiving services at Athens Nurses Clinic. **Table 2** shows the sociodemographic characteristics of these 4 participants. Median age (min, max) for the participants was 47 (45-52) years. Two participants were Hispanic white and 2 were black. All participants were able to speak English. Median monthly income (min, max) was $950 (0-1,840), all falling under the federal poverty line. None of

the participants had health insurance, and only 2 of the 4 participants received food assistance, though the type of food assistance was not specified. Median HbA1c (min, max) was 6.5 (6.0-10.6) for the sample. For one participant, only 2 HbA1c values were documented in the medical record and were used to calculate average HbA1c. Participants were categorized into 2 groups as determined by average HbA1c values. Three participants were determined to have good glycemic control (GC) (HbA1c < 7%), while 1 participant was determined to have poor GC (HbA1c ≥ 7%). **Table 3** shows the household structure and caregiving relationships of the study sample. Median family size (min, max) was 3.0 (3.0-4.0), and 3 of the 4 participants were single. Two participants were documented as head of household. The median number of dependents (min, max) was 2.0 (1.0-2.0) with median age (min, max) of 11.0 (4.0-24.0) years.

The poor GC participant received no food assistance and reported very low food security. In regard to household structure, the poor GC participant was married with younger children and was not the head of household, compared to the good GC group, who were all single and more likely to be head of household.

Medical history of the participants is shown in **Table 4**. Median BMI (min, max) for the 4 participants was 31.5 (29.0-33.0) kg/m^2, which falls into class I obesity. All four participants were on diabetes medication. Median number of medical diagnoses (min, max) for all participants was 6.0 (4.0-9.0), some of which included insomnia, gout, asthma, psoriasis, chronic pain, gastroesophageal reflux disease, and hepatitis C.. All had at least three diet-related chronic conditions, including obesity, diabetes, hypertension, or dyslipidemia. The poor GC participant experienced fewer diagnosed medical conditions,

but more diet-related chronic conditions than did the good GC group. A complete list of medical conditions is shown in **Table 5.**

Diabetes self-management

As shown in **Table 6**, for the total sample of participants, the median (min, max) self-reported adherence to diet-related management practices over the past week was 4.4 (3.8-5.4). Higher adherence was reported for following an eating plan over the past week and on average over the past month, but lower adherence for following practices of eating 5 or more fruits and vegetables. For participants overall, median (min, max) exercise adherence in the past week was greater for general physical activity, 6.0 (4.0-7.0) days, than for specific exercise sessions, 2.5 (0-7.0) days. In regard to blood glucose testing, although participants reported on average higher adherence to testing blood glucose, they had lower adherence to testing frequency as recommended by their physicians. Additionally, participants reported checking their feet every day, but checked the inside of their shoes less frequently.

Compared to the good GC group, the poor GC participant reported poorer adherence to overall diet practices. More specifically, the poor GC participant followed a healthful eating plan over the past month less often and spaced out carbohydrates less often. Reported median adherence to eating 5 or more servings of fruits and vegetables a day was the same between the good GC group and the poor GC participant. The poor GC participant reported higher adherence to blood sugar testing than the good GC group, but poorer adherence to testing blood sugar in terms of the number of times recommended by a physician. For foot care, overall adherence was higher in the poor GC participant, specifically contributed by higher adherence to checking the inside of shoes.

Food security

Overall, none of the participants were categorized as having high food security. One of the 4 participants had marginal food security, 2 had low food security, and 1 had very-low food security. The poor GC participant reported very-low food security.

Dietary intake

Results of dietary intake assessment are shown in **Table 7**. Median estimated energy needs (min, max) for the four participants were 1,925 (1,575-2,300) kcal. The median reported energy intake (min, max) over 24 hours for the total sample was 922 (876-1,770) kcal, much less than estimated energy needs. Median macronutrient distribution fell into the distribution recommended by ADA. Carbohydrates made up 47.8 (40.7-48.5) %, total fat made up 31.4 (18.8-39.5)%, and saturated fat made up 9.7 (6.5-13.4) % of energy intake over 24 hours. In regard to dietary pattern for the total sample, median (min, max) consumption of fiber was 10.5 (7.0-19.5) g and intake of whole grains was 0.6 (0-3.8) servings. Median vegetable consumption was 0.3 (0-2.0) servings and fruit was 0.4 servings (0-0.8). Self-reported dietary intake through diet recall showed that the poor GC participant consumed lower amounts of total and saturated fat, higher amounts of fiber and whole grains, but fewer fruits and vegetables compared to the good GC group. These findings of fruit and vegetable consumption are inconsistent with adherence reported through the SDSCA, which found higher reported adherence to fruit and vegetable consumption in the poor GC participant.

Psychological factors

Table 8 shows the results of psychological factors influencing diabetes management. Overall, the poor GC participant reported higher levels of depression,

anxiety, and stress than the good GC group. Additionally, the median (min, max) score for diabetes-related emotional distress for the total sample was 9.5 (3.0-15.0), indicating possible diabetes-related emotional distress. The score for diabetes-related distress was also more pronounced in the poor GC participant than the good GC group.

Table 1. Results from recruitment of eligible participants

Eligible Participants N=22	Recruitment Method					
	Call					Mail
	By UGA researchers				By Clinic Staff	By UGA researchers
	1st attempt	2nd attempt	3rd attempt	4th attempt	Attempt	Mail recruitment
1	CB	LM	LM	LM		
2	LM	LM	LM	LM		Recruited Part. 3
3	LM	LM	LM	LM		
4	LM	LM	LM	LM		
5	CB	LM	LM	LM		
6	PD					
7	LM	LM	LM	LM		
8	CB	LM	LM	LM		
9	CB	LM	LM	LM		
10	PD					
11	PD					
12	LM	LM	LM	Recruited, but no show		
13	LM	LM	LM	LM		
14	LM	LM	LM	LM		
15	LM	Recruited Part. 2				
16	CB	Interpreter not available			Recruited Part. 4	
17	LM	Interpreter not available				
18	Recruited Part. 1					
19	LM	Interpreter not available				
20	CB	Interpreter not available				
21	NT					
22	LM	Interpreter not available				

	No. eligible participants (n=22)
Unable to speak with	12 (54.6%)
Requested call back, but no subsequent contact	5 (22.7%)
Recruited, but no show	1 (4.5%)
Total recruited and participated	**4 (18.2%)**
By mail and participated	1 (4.6%)
By phone and participated	3 (13.6%)

Note: CB: requested call back
LM: left message
PD: Phone disconnected
NT: No transportation

Table 2. Sociodemographic characteristics of participants

Median (min, max) or %	Total (n=4)	HbA1c < 7 (n=3)	HbA1c ≥ 7[1] (n=1)
Age (y)	47 (45, 52)	48 (45, 52)	46
Race/ethnicity			
Hispanic White	50%	33.3%	100%
African American	50%	66.7%	0%
Monthly household income ($)	950 (0, 1840)	600 (0, 1840)	1,300
Having health insurance	0%	0%	0%
Receiving food assistance	50%	66.7%	0%
Food security			
High food security	0%	0%	0%
Marginal food security	25%	33.3%	0%
Low food security	50%	66.7%	0%
Very low food security	25%	0%	100%
HbA1c[2] (%)	6.5 (6.0, 10.6)	6.5 (6.0, 6.6)	10.6
HbA1c documentation interval	3.5 (3.0, 12.5)	3.5 (3, 12.5)	3.5

[1]HbA1c ≥ 7% indicates poor blood glucose control in diabetics

[2]Mean based on average of past 3 documented HbA1c records. One participant had record of only 2 HbA1c values.

Table 3. Household structure and caregiving relationship of participants

Median (min, max) or %	Total (n=4)	HbA1c < 7 (n=3)	HbA1c ≥ 7 (n=1)
Marital status			
Single	75%	100%	0%
Married	25%	0%	100%
Head of household	50%	66.7%	0%
Family size	3.0 (3.0, 4.0)	3.0 (3.0, 3.0)	4.0
No. of dependents	2.0 (1.0, 2.0)	2.0 (1.0, 2.0)	2.0
Type and number of dependents			
≥1 child	100%	100%	100%
≥1 grandchild	25%	33.3%	0%
Age of dependents, years	11.0 (4.0, 24.0)	11.0 (4.0, 24.0)	10.0 (7.0, 13.0)
Primary caregiver	75%	66.7%	100%
≥1 dependent contributing to household income	25%	33.3%	0%

Table 4. Medical history of participants acquired from medical records

Median (min, max) or %	Total (n=4)	HbA1c < 7 (n=3)	HbA1c ≥ 7 (n=1)
BMI[1]	31.5 (29.0, 33.0)	31.0 (29.0, 33.0)	32.0
No. medications	6.0 (4.0, 9.0)	6.0 (4.0, 9.0)	6.0
Taking prescribed diabetes medication[2]	100%	100%	100%
No. documented medical conditions	6.0 (4.0, 9.0)	6.0 (6.0, 9.0)	4.0
No. documented diet-related chronic conditions[3]	3.0 (3.0, 4.0)	3.0 (3.0, 3.0)	4.0

[1]Body mass index is measured in kg/m^2
[2]Diabetes medication includes metformin and/or glipizide
[3]Diet-related chronic conditions include obesity, diabetes, hypertension, and dyslipidemia

Table 5. Medical conditions of participants acquired from medical records

Medical diagnosis	Frequency (n=4)
Type 2 diabetes[1]	4
Obesity[1]	4
Hypertension[1]	4
Dyslipidemia[1]	1
Chronic pain	3
Insomnia	1
Gout	1
Asthma	1
Psoriasis	1
Hepatitis C	1
Carpal tunnel syndrome	1
Arthritis	1
Gastroesophageal reflux disease	1
Schizophrenia/depression	1

[1]Diet-related chronic conditions

Table 6. Diabetes self-management of participants

Median (Min, Max)	Total (n=4)	HbA1c <7 (n=3)	HbA1c ≥7 (n=1)
Diabetes Management[1] (days over past week)			
Diet			
Followed eating plan over past month	6.5 (4.0, 6.0)	7.0 ±0.6 (6.0, 7.0)	4.0
Ate 5 or more fruits and vegetables	3.0 (0, 3.0)	3.0 (0, 3.0)	3.0
Ate high fat foods[2]	5.5 (0, 7.0)	6.0 (0, 7.0)	5.0
Spaced out carbohydrates	4.0 (2.0, 7.0)	5.0 (3.0, 7.0)	2.0
Followed a healthy eating plan	5.0 (5.0, 7.0)	5.0 (5.0, 7.0)	5.0
Total	4.4 (3.8, 5.4)	4.8 (4.0, 5.4)	3.8
Exercise			
Did at least 30 min physical activity	6.0 (4.0, 7.0)	7.0 (4.0, 7.0)	5.0
Did specific exercise session	2.5 (0, 7.0)	2.0 (0, 7.0)	3.0
Total	3.75 (3.0, 7.0)	3.5 (3.0, 7.0)	4.0
Blood glucose testing			
Tested blood sugar	5.0 (1,7)	3.0 (1.0, 7.0)	7.0
Tested blood sugar # times recommended by physician	3.0 (1.0, 7.0)	5.0 (1.0, 7.0)	1.0
Total	4.0 (1.0, 7.0)	4.0 (1.0, 7.0)	4.0
Foot care			
Checked feet	7.0 (7.0, 7.0)	7.0 (7.0, 7.0)	7.0
Checked inside of shoes	3.5 (0, 7.0)	0 (0, 7.0)	7.0
Total	5.25 (3.5, 7.0)	3.5 (3.5, 7.0)	7.0

[1] Measured using Summary of Diabetes Self-Care Activities; Total score for each category is calculated from the mean of all items within category. Higher score indicates better diabetes management (Range: 0-7)

[2]Scores for high fat foods was reversed so that 0=7, 1=6, 2=5, 3=4, 4=3, 5=2, 6=1, 7=0

Table 7. Dietary intake of participants relative to ADA recommendations

Median (Min, Max)	ADA[1] Recommendation	Total (n=4)	HbA1c < 7 (n=3)	HbA1c ≥ 7 (n=1)
Energy needs[2] (kcal)	N/A	1925 (1575, 2300)	2000 (1575, 2300)	1850
Calories	N/A	922 (876, 1770)	931 (913, 1770)	876
% CHO	45-65%	47.8 (40.7, 48.5)	47.2 (40.7, 48.5)	48.4
% Fat	20-35%	31.4 (18.8, 39.5)	35.2 (18.8, 39.5)	27.6
% Sat fat	<10%	9.7 (6.5, 13.4)	12.7 (6.5, 13.4)	6.6
Fiber (g)	25	10.5 (7.0, 19.5)	8.2 (7, 19.5)	12.8
Whole grains[3]	3-5	0.6 (0, 3.8)	0.4 (0, 0.7)	3.8
Vegetables[3]	3	0.3 (0, 2.0)	0.3 (0.3, 2.0)	0
Fruits[3]	2	0.4 (0, 0.8)	0.7 (0.1, 0.8)	0

[1]American Diabetes Association recommendations for nutrition therapy
[2]Energy needs calculated for weight maintenance based off Mifflin-St. Jeor formula using actual body weight
[3]Unit of measure is in servings, as defined by the 2010 Dietary Guidelines for Americans

Table 8. Psychological factors influencing diabetes management

Median (Min, Max)	Total (n=4)	HbA1c <7 (n=3)	HbA1c ≥7 (n=1)
DASS-21[1]			
Depression	5.0 (0, 10.0)	4.0 (0, 10.0)	6.0
Anxiety	5.0 (4.0, 10.0)	4.0 (4.0, 6.0)	10.0
Stress	7.0 (4.0, 14.0)	6.0 (4.0, 14.0)	8.0
Diabetes-related emotional distress[2]	9.5* (3.0, 15.0)	6.0 (3.0, 13.0)	15.0*

[1] Higher score indicates higher degrees of depression, anxiety, or stress (Range: 0-42)
[2]Scores ≥8 indicate possible diabetes-related emotional distress which warrants further assessment (Range 0-20)
*Higher degree than normal (> 8)

CHAPTER 5

DISCUSSION

The purpose of this feasibility study was to understand the status of and factors associated with diabetes management in low-income female caregivers. In addition, this study examined the feasibility of establishing a new partnership with a non-profit community organization, Athens Nurses Clinic.

Key findings

While interpretation of results is limited due to the small sample size (n=4), findings provide a snap shot of objective and self-reported diabetes self-management and related factors in this particular study population. All 4 participants fell below the poverty line and cared for dependents with a wide range of ages ranging from 4 to 24, and including both children and grandchildren, which is similar to the trend in increasing multi-generational American households in the past three decades (Fry and Passel 2014).

Diabetes self-management assessed by HbA1c

Overall, participants had good diabetes management as assessed by HbA1c. Specifically, 3 of the 4 participants had good glycemic control, and 1 participant had poor glycemic control. We expected that majority of these women would have elevated HbA1c values due to the nature of the sample. These women were, however, receiving treatment services for diabetes and all were on oral medication for diabetes.

Some differences were noted between those with poor GC and good GC. The poor GC participant received no food assistance compared to the good GC group, the

participant had lower food security status. The poor GC participant also had a larger family size than the good GC group, and thus greater resources distribution. As reflected in the findings, one would expect that a household with a higher need, but no food assistance would experience a more severe degree of food insecurity. According to the USDA Economic Research Service, 40% of food-insecure households receive no food assistance from major programs including SNAP, WIC, or free or reduced-priced school lunch (Coleman-Jensen et al 2014b). Food assistance likely ameliorates food insecurity to supplement household income. The results of this study are similar to what has been found in previous studies concerning the association between food insecurity and poor diabetes management (Lyles et al 2013; Seligman et al 2012).

The poor GC participant experienced more diet-related chronic conditions than those with good GC. It is possible that the need to manage multiple chronic conditions adds additional challenges to good management practices, in the form of physical and emotional symptoms, financial strain, coordination of medication (Liddy et al 2014). The management of one condition could be prioritized over the management of another, affecting overall health.

Diabetes self-management assessed by reported practices

Contrary to assessment by HbA1c, participants on average had lower diabetes self-management as assessed by reported practices. Reported average energy intake in the study sample was very low relative to weight status, which may indicate that participants underreported food intake. Furthermore, the four participants reported very low median intake of fruit and vegetables that did not meet recommendations by the Dietary Guidelines for Americans and the ADA (USDA 2010; Evert et al 2013). The median

reported intake for the total sample did not meet the recommended 3-5 servings of whole grains and 25 g of fiber (USDA 2010; Evert et al 2013). Diets of the study sample were limited in high fiber rich foods such as fruits, vegetables, and whole grains shown to have positive effects on diabetes incidence and blood glucose control in a meta-analysis of epidemiological studies (Maghsoudi et al 2012).

Reported frequency of diet-related management activities revealed conflicting results with the diet recall. Overall, contrary to what the diet recall indicates with low consumption of high fiber foods and whole grains, the SDSCA revealed high frequency of following a healthful eating plan over the past week and the past month. Discrepancies between the diet recall and assessment of diet-related management practices bring to light a possible deficit in participant nutrition knowledge. Findings of low fruits and vegetables intake from the SDSCA, however, were consistent with the diet recall. The reported low fruit and vegetable intake is consistent with previous studies in food-insecure, low-income women (Duffy et al 2009; Tarasuk et al 2007).

Overall, participants had higher median adherence to at least 30 minutes of physical activity, but much lower for specific exercise sessions. More physically demanding blue-collar occupations or limited access to transportation, forcing them to walk to desired destinations, could explain greater amounts of activity, apart from planned exercise. Poor adherence to testing blood glucose the number of times recommended by their providers could be explained by the reported difficulty female caregivers experience in testing blood glucose in addition to caring for their families and other responsibilities (Cathron et al 2010, Cathron et al 2014). Lack of adherence to the

recommended frequency of blood glucose testing could be a result of added burden of childcare.

Some diabetes management practices differed between the good GC group and the poor GC participant. Lower adherence to diet-related management practices in the poor GC participant reflects the integral role nutrition therapy plays in diabetes management (ADA 2013). Surprisingly, foot care activities were higher in the poor GC participant than the good GC group. One possible explanation for this is that foot care may be easier to adhere to and has fewer barriers, such as time and cost, compared to practices of good nutrition, exercise, and blood glucose testing.

Significance of psychological factors in diabetes self-management

Mental health assessment showed that, on average, stress was highest in the 4 participants compared to other measures of depression and anxiety. While this measure does not directly measure specific stress or burden such as caregiving burden, it is possible that these higher levels may in part be contributed to caregiving as found in multiple qualitative studies (Dammann and Smith 2009; Samuel-Hodge et al 2000). By comparison, the poor GC participant experienced a higher median degree of depression, anxiety, and stress. Higher degrees of poor mental health could be related to poor diabetes management and diabetes-related emotional distress, which was much higher in the poor GC participant compared to the good GC participants. Elevated diabetes-related emotional distress indicates feelings of fear and worry related to diabetes management and possible complications (McGuire et al. 2009). It is likely that individuals with uncontrolled diabetes worry more about the risk serious complications than those who have diabetes under control.

Reported vs. objective management practices

A comparison of diabetes management assessed by HbA1c versus self-reported management practices reveals inconsistencies. While HbA1c showed that majority of the participants had good GC, report of management practices showed relatively poor adherence in those with good GC. It is clear that though HbA1c is an objective measure, HbA1c alone may be limited to predict the adherence to management practices.

Feasibility

The target population of this study was low-income mothers and other female caregivers with diabetes who are a very specific subset of the population. Many challenges were presented in accessing and reaching them as identified in Bonevski et al's (2014) systematic review on barriers to targeting socioeconomically disadvantaged groups for health and medical research. Several relevant strategies were adopted to reach the target population. As an initial effort, this study has built collaboration with a community organization that is in communication with the target population and recruited a convenience sample through that organization (Bonevski et al). Initial attempts were made to collaborate with a local WIC clinic and a Mercy Health Center, a safety net clinic, and the ultimate collaboration with Athens Nurses Clinic.

UGA researchers have carefully devised strategies to overcome barriers in accessing the difficult to reach target population and to develop study protocol reflecting unique situation of the collaborating organization throughout the design and conduct of the study. To come up with best recruitment approaches, inputs and suggestions from the executive director and volunteer coordinator of Athens Nurses Clinic were sought. The study protocol, including recruitment strategy was revised several times to best fit Athens

Nurses Clinic and to address unique IRB issues, all of which resulted in necessary delays in finalizing the study protocol and conduct of this study. For example, completion of required staff IRB CITI training took longer than anticipated. This was likely due to the staff's more pressing job responsibilities at the clinic, as well as technical difficulties establishing IRB CITI training login information. Recruitment, therefore, began later than originally planned.

Restrictive eligibility criteria was one barrier experienced in this study. It has been suggested that study inclusion criteria, if too restrictive, should be broadened to increase the representativeness of the sample (Bonevski et al 2014). Upon screening eligible participants, eligibility criteria were expanded from low-income mothers to low-income female caregivers due to the limited pool of patients meeting criteria, which prompted the need for further IRB approval and delay in recruitment. Broadening eligibility criteria expanded our pool of eligible participant, although with a limited effect.

Recruitment

During the recruitment process, we have faced several barriers. Cultural-related issues were a significant barrier to recruitment. With regard to recruitment of non-English speaking participants, utilizing on-site interpreters from the organization has been shown to improve recruitment (Bonevski et al 2014). This study used this strategy by using a Spanish interpreter on staff at Athens Nurses Clinic. The interpreter was culturally competent and contributed to the recruitment process for Spanish-speaking patients. One issue that was encountered with using an interpreter on staff was that the interpreter was

not always available for assisting with recruitment. Recruitment for Spanish-speaking participants was, therefore, limited to the interpreter's availability during clinic hours.

Low response rate was an additional barrier to recruitment for this study. Recruitment from this low-income patient population was very low. Despite following recommendation from the clinic collaborators for best recruitment approaches, telephone recruitment did not prove to be an effective strategy. More than half of the eligible patients could not be reached for this study. Telephone recruitment may not be the most effective method to use in low-income, safety net populations. One possible reason for this is that some individuals who pay per minute may only turn their phones on if they are making or expecting calls. Another possible explanation, as suggested by clinic staff, is that they may not answer calls if they are not familiar with the number, to avoid calls from tax collectors or immigration. For this reason, telephone recruitment was conducted from Athens Nurses Clinic telephones, in hopes to eliminate the potential barrier of mistrust.

A study by Choudhury et al (2012) utilized direct mail survey and reported a trend in higher survey response rate from hand written envelopes compared to printed envelopes, though not statistically significant. This strategy, which was used in this current study as an indirect recruitment method by mailing flyers to patients' homes, did not elicit a much greater response, prompting only one eligible patient to respond to the flyer. More direct methods such as on-site recruitment may be most effective for this population. As suggested by a clinic collaborator, recruitment at the time of the patient's appointment may be the most effective way of gaining patient interest.

Additional strategies to improve low response rates recommended in Bonevski et al's (2014) review include outreach/home visits and assistance with transport or childcare. The use of these strategies would have potentially enhanced convenience for low-income female caregivers and may have prompted greater response.

Data collection

An initial intention was to interview participants in conjunction with the patient's next clinic appointment, as recommended by the clinic staff. This method would have required significantly more time to complete data collection, because participants' appointments were scheduled over the course of a couple months. Due to time constraints and delayed study implementation, researchers chose to schedule separate appointments for in-person interviews, which allowed an accelerated data collection.

This study used methods of interviewer-administered and interviewer-guided questionnaires that were validated in similar populations to eliminate low literacy and low education barriers. As mentioned previously, this study was prepared to use a culturally competent Spanish interpreter. Interpretation for data collection was not necessary, however, because all participants were able to speak English despite cultural background.

In regard to the length of the questionnaires, it was suggested by clinic collaborators that the questionnaires should be shorter in order to keep participants engaged. Shorter questionnaires would reduce respondent burden. The ASA24 diet recall portion of the interview required much of the participant's time. Utilizing dietary intake measures that are simple, accurate, and less demanding could be more effective in a low-income population. Diet recalls were conducted on-site and interviewer-guided.

Computer access was also provided in order to eliminate Internet access and computer literacy barriers.

It has been shown that online diet recall with a multiple pass method such as the ASA24 has found an accuracy of about 80% of actual intake (Kirkpatrick et al 2014). Measures of dietary intake in this study, however, do not seem to reflect actual intake. Participants in this study significantly under-reported energy intake, as evidenced by BMI. One study looking at Brazilian women found that under-reporting energy intake was associated with higher BMI's, social desirability, body dissatisfaction, and lower income (Scagliusi et al 2009). Because the diet recalls for this present study were interviewer-guided, social desirability, which is the tendency of survey respondents to respond in a way that they see as favorable to others, may have influenced under-reporting to some degree. It is, therefore, difficult to assess how dietary intake was related to diabetes management in study participants.

Conversely, the psychological measures used in this study may better reflect such factors to diabetes management. Both the DASS-21 and the PAID-5 were able to assess differences in mental health between good and poor glycemic control and elevated diabetes-related distress, overall. Because response variation was found, it is likely that participants varied in degrees of poor mental health status. The findings found from these measures are also supported in previous studies linking diabetes-related distress with diabetes management (Fisher et al 2009; Seligman et al 2012). In this study, measures of specific stress were not evaluated to assess caregiving burden in female-caregivers. To the knowledge of the researchers of this study, no assessment is available to measure caregiving burden among a heterogenous sample of caregivers. The Parenting Stress

Index (PSI), is one assessment that has been utilized in a number of studies (Abidin, 1995; Reitman 2002). The PSI, however, was developed to measure parenting stress in caregivers with children under the age of 12.

Strengths

To our knowledge, this is the first study to assess factors associated with diabetes management in low-income female caregivers. Stress has up until now never been quantitatively evaluated in relation to caregiver status in women with diabetes. This study established a new partnership with a community organization that had no previous connection to nutrition research targeting its patients. By working closely with the staff at Athens Nurses Clinic, we were able to better understand the dynamics of this hard-to-reach population and learn how to implement similar studies in the future. In addition, the use of financial incentives in the form of a diabetic-friendly cookbook and $10 supermarket gift card enhanced eligible participant interest in study participation.

The data collected in this study is rich and includes data on general participant characteristics, medical conditions, medication use, health insurance, food assistance participation, and household and caregiving demographics. In addition, this study collected data on a number of influencing factors to diabetes management including food security status diabetes self-management practices, diet quality, depression, anxiety, stress, and diabetes-related emotional distress. The use of secondary data from participant medical records provided information about medical history that is not easily accessible in low-income populations. HbA1c was used as an objective measure for long-term glycemic control and is a trustworthy marker of diabetes management. Thus, through HbA1c data, we were able to see the effect of diabetes self-management activities on

glycemic control in the study sample. This study laid the groundwork for further investigation of diabetes management in low-income female caregivers with studies on a larger scale. Questionnaires were interviewer-administered in order to eliminate barriers of low literacy and low education in this population. Additionally, we used two methods to assess diet quality, which gave us a better understanding of diet quality and practices than diet recall alone. The use of multiple psychological assessment showed that mental health status influencing diabetes management is multidimensional.

Limitations

As with all research studies, this study is not without limitations. This study is cross-sectional in nature, and thus, captures only one point in time. Longitudinal studies may be more appropriate for this type of study. Recruitment was a challenge due to the hard-to-reach nature of the population, restrictive eligibility criteria, and chosen telephone recruitment method. This study had low rates of contact with eligible participants during recruitment and was, therefore, limited to a small sample of 4 participants. The sample was also very heterogeneous, with a variety of caregiving relationships, which limited our ability to analyze sample data beyond descriptive statistics. Initial intentions with a larger sample were to analyze the association between food security status and diabetes management. Factors associated with diabetes management would ideally be assessed for mediation between food security and diabetes management. Moreover, these women may not be representative of all female caregivers, and more specifically, low-income mothers with diabetes. Another caveat is that caregiving may be temporary or transitory. The length of time and permanency as a

caregiver was not assessed in this study, thus burden and strain on finances may be different and difficult to compare between participants.

All questionnaire measures were self-reported and interviewer-administered. While this method has its strengths, it also opens up the risk for respondent error or social desirability bias. Participants may feel more comfortable to answer honestly if they answer assessment privately and individually. Another limitation is that food security status was not measured for children within the household. Assessment of child food security would have revealed a deeper effect on how caregivers approach and prioritize feeding their families with limited food resources. The US Household Food Security Survey Module 6-item short form was used instead or the 18-item version in order to reduce respondent burden (Blumberg et al 1999). Additionally, dietary intake as measured by the ASA24 was significantly under-reported and only assessed one day's intake. This limits our ability to evaluate connections between food insecurity, diabetes management, and its outcomes. A 3-day diet recall would have given us a more accurate picture of dietary habits and patterns.

Another significant limitation is that this study did not use a direct measure of caregiving burden or parenting stress. While general mental health and stress was evaluated, it cannot be assumed that the stress measures are a result of caregiving burden, though it may contribute in part. The use of a more homogenous sample could allow opportunity for caregiving burden assessments that have been developed for specific subsets of the caregiving population.

Lastly, this study did not contain a control group to assess differences between food-secure diabetic women versus food-insecure diabetic women, or caregiving diabetic

women versus non-caregiving diabetic women. Future studies could potentially hone in on those factors to assess the degree of influence each factor has on diabetes management and glycemic outcomes.

Implications

This study has several implications for research, practice, and policy.

Research

This study serves as a pilot and feasibility study for future research targeting low-income female caregivers and diabetes management. This study identified barriers and strategies to establishing new partnerships with community organizations, as well as recruitment and data collection in a socioeconomically disadvantaged population. Researchers should thoroughly inform collaborators from partnering community organizations, share ownership of research findings, and ensure the beneficial impact of research findings on organization programs and services (Bonevski et al 2014). The most effective way to target low-income female caregivers or mothers with diabetes would be to create a network of partnerships to ensure a larger population pool.

Recruitment of this sample is difficult to reach. Future researchers will need to utilize multiple recruitment methods to engage this low-income population. It is important to be sensitive to the barriers faced by this type of population, and to incorporate strategies that will eliminate those barriers, such as on-site recruitment, multiple contact attempts, mail-ahead flyers, and use of incentives. Accommodating other possible barriers such as providing transportation and childcare could increase interest. Safety net clinics may not be the most ideal organization to target as many of the patients are older, and potentially have older children. Organizations tailored to meet the needs of

low-income mothers, such as the WIC program, may be the most effective target for recruitment. Partnership with federal programs, however, may be challenging due to the need for overarching administration approval, as was experienced in this present study. Researchers should be mindful of potential respondent burden and work to reduce burden without compromising the integrity and validity of chosen measures and assessments. Measures specific to caregiving burden should be utilized to directly capture its influence on diabetes management. It is important, however, to ensure its validity in the age range of the study samples' children. An additional measure of child behavior could give a clearer picture of caregiving burden.

Practice

Findings from this study have a marked effect on health services and community programs. Overall, participants had poor adherence to good diet-related diabetes management. While Athens Nurses Clinic offer nutrition education classes, the safety net clinic does not have a registered dietitian on staff and does not provide individualized nutrition services. Individualized nutrition services are an important part of diabetes management, because each individual with diabetes is unique. Community health centers and safety net clinics are potential work areas for dietitians. Patients should be screened for food insecurity every couple of months. Measures that accurately assess diet quality and food security of patients should be used in order to better serve their management needs. Food frequency questionnaires may be the most efficient way to obtain information on diet quality in a clinic setting. Low-income patients may experience poorer mental health due to financial stress, caregiving burden, and disease management. Additional counseling services should be available to patients so that coping skills can be

established. Collaboration between the medical team, a dietitian, and a counselor would allow for more effective treatment and education. Implementing such services to improve good diabetes management could ultimately reduce the medical costs for the clinic. It is recommended that clinics assess the number of low-income caregivers with diabetes in need of comprehensive services.

Policy

Patients at safety net clinics likely do not qualify for Medicaid coverage, but also do not have high enough income to purchase private insurance. Medicaid expansion through the Affordable Care Act aims to close that coverage gap, but it is voluntary for states to participate (CMS 2015). Unfortunately, as of 2014, 3.8 million Americans fell into the coverage gap (KHF 2014). There is a need for multidisciplinary services offered to those that fall into the coverage gap and require constant need in order to manage chronic conditions, such as diabetes.

Safety net clinics serving low-income female caregivers have the potential to collaborate with other programs, such as the WIC program. WIC already serves as a block grant program to support low-income mothers and their young children with nutrition assistance, counseling, and education. According to personal communication with the WIC clinic manager for Athens-Clarke County, GA, diabetes services have been scaled back in the district. The primary approach within this WIC clinic in implementing is to refer out to free clinics in town such as Athens Nurses Clinic and Mercy Health Center. Clients can receive basic nutrition counseling from WIC nutritionists. Because registered dietitian staffing within the health district is limited to 2 dietitians, however, diabetic WIC clients cannot be guaranteed medical nutrition therapy for diabetes if

needed. Besides education and referrals, the WIC clinic in Athens-Clarke County does not have the resources to treat and continuously monitor diabetic clients.

With referrals from WIC out to clinics such as Athens Nurses Clinic, it is important for the clinic to provide high quality, holistic services for diabetes. Collaboration between safety net clinics and the WIC program to provide services for diabetic patients would better serve this low-income population with caregiving responsibilities. Additionally, in regard to WIC client assessment, it may be beneficial to include an assessment caregiving burden, such as the PSI in order to gauge potential barriers to diet or disease management.

CHAPTER 6

CONCLUSION

Low-income female caregivers have higher rates of poverty (DeNavas-Walt and Proctor 2014; Ellis and Simmons 2014) and are more likely to be food-insecure (Coleman-Jensen et al 2014b). Those who experience poverty have a greater risk of poor health and have higher prevalence of chronic medical conditions and limited physical functioning (Weinreb et al 1998). Food insecurity contributes to these higher rates of chronic diseases, including type 2 diabetes (Seligman et al 2007). Management of diabetes can be difficult for this particular population.

This study tested the feasibility of both establishing a new partnership with a local safety net clinic and reaching this socioeconomically disadvantaged group of female caregivers. We proposed and evaluated a number of factors with potential to influence diabetes management and glycemic outcomes including food security status, diet quality, caregiving burden, and diabetes-related emotional distress. Through the use of secondary data from patient medical records and primary data collection through one-time, in-person interviews, we were able to obtain data on a variety of sociodemographic characteristics, household and caregiving demographics, medical history, glycemic control, food security status, diet quality, diabetes self-management practices, and mental health status.

Despite a limited sample size, we found that overall these low-income female caregivers with diabetes had poor diet quality and recommended diabetes-related diet

adherence. Additionally, these women reported higher levels of diabetes-related emotional distress, which may be an indicator of strain on diabetes management. Although it is difficult to conclude differences found between those with good GC versus poor GC, we found that one of the 4 participants had poor GC. The poor GC participant experienced lower food security, more diet-related chronic conditions, and poorer mental health.

This study encountered a number of barriers to locating a sample, recruitment and data collection due to the hard-to-reach nature of low-income caregiving women. It is recommended that future studies utilize multiple avenues for recruitment, by partnering with multiple community organization and using a variety of recruitment methods. This study lays the ground work for future studies that target this particular demographic of the population.

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APPENDIX A

TELEPHONE RECRUITMENT SCRIPT

Client name: _____

Hello!

My name is _____ calling from Athens Nurses Clinic.

[*If UGA researcher is contacting]:* We obtained your contact information from Athens Nurses Clinic.
I am contacting you because you are potentially eligible for a study going on at the clinic. The study is being conducted by researchers from the University of Georgia's Department of Foods and Nutrition and is looking at factors that might be associated with the management of type 2 diabetes. We are particularly interested in how limited access to affordable, healthy foods affects diabetes management. We are looking specifically at low-income women with dependents because we want to assess how the burden of supporting dependents affects the relationship between food insecurity and diabetes management. Also, we are investigating how different levels of knowledge about diabetes affect diabetes management and what other factors, like attitude towards diabetes, might influence that relationship. The study consists of two questionnaires and dietary recall, and will only take a total of about an hour of your time.

Do you think you might be interested in participating in this study?

[If No] Thank you very much for your time.

[If Yes] Great, now before enrolling you in this study, we need to ask you some questions to confirm your eligibility. So now what I would like to do is ask you a few yes or no questions. This should only take about 5 minutes.

These questions impose no risk of discomfort.

The information I receive from this phone call is confidential, including your name and contact information. All information will be kept under lock and key. If you are found ineligible after these questions, the information I have recorded will be immediately destroyed.

Participation is voluntary. You have the right to withdraw at any time.

Do I have permission to ask you these questions to determine eligibility?

[If Yes, proceed]

1. Are you currently a client at Athens Nurses Clinic? Yes No
2. Are you a woman currently over the age of 18? Yes No
3. Has a medical professional ever told you that you have type 2 diabetes? Yes No
4. Do you have any dependent children? Yes No
5. Are you currently pregnant? Yes No

[If ineligible] Unfortunately, you do not meet the criteria for this particular study. We appreciate your interest and thank you for your time.

[If eligible] You meet all of the criteria to participate in this study.

We invite you to participate in our study, which will be conducted at Athens Nurses Clinic. The study will require just one, hour-long visits. We will need to schedule a time for you to come in to complete the questionnaires and diet recall. For your participation, you will receive a free diabetic-friendly cookbook and a $10 grocery store gift card.

Would you like to participate in this study? Yes No

[If No] Okay, well thank you for your time.

[If Yes] Okay, let's schedule a time for you to come in. [*proceed to schedule a time*]

If you have any questions regarding the study please contact Rachel Laudel at 404-561-2763. Questions or concerns about your rights as a research participant should be directed to the Institutional Review Board at 706-542-3199; email address irb@uga.edu.

Thank you for your time! You will be directed through the study process at you next clinic appointment.

APPENDIX B

RECRUITMENT FLYER

Research Participants Needed for a Nutrition & Diabetes Study

Are you a woman with diabetes enrolled at the Athens Nurses Clinic?

We invite you to participate in a study from the Department of Foods and Nutrition at the University of Georgia

This study will examine factors associated with diabetes management in low-income women with financial dependents

Just one 1-hour session

Get a $10 grocery store gift card and a free diabetic cookbook!

You may be eligible if you are:

- A woman with at least 1 financial dependent
- Diagnosed with type 2 diabetes
- A participant in the Athens Nurses Clinic
- Over 18 years old

Participants will be asked to:

- Participate in one session, lasting about 60 minutes
- Complete a series of questionnaires and diet recall

For more information please contact:

Rachel Laudel
404-561-2763, laudel@uga.edu

Department of Foods and Nutrition
University of Georgia
IRB # STUDY00001139
Principal Investigator: *Dr. Jung Sun Lee*
leejs@uga.edu

APPENDIX C

INFORMED CONSENT FORM

Researcher's Statement

We are asking you to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you that information about the study so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

Principal Investigator: *Dr. Jung Sun Lee*
Associate Professor
Foods and Nutrition
University of Georgia
leejs@fcs.uga.edu

Purpose of the Study

The purpose of this study is to examine factors that might be associated with diabetes management in low-income diabetic women with dependents. One of the two main purposes of our study is to see how limited access to affordable, healthy foods affects the management of type 2 diabetes. We are particularly interested in how the added stress of taking care of children among low-income women would affect the relationship between food insecurity and diabetes management. Another main goal of our study is to investigate how different levels of knowledge about diabetes affect diabetes management. We are also interested in examining how general education, diabetes education, and attitude toward diabetes influence the relationship between diabetes knowledge and diabetes management. You are being asked to participate in this study because 1) you are a woman with at least one dependent, 2) you have a diagnosis of type 2 diabetes, 3) you are a client at Athens Nurses Clinic, and 4) you are over the age of 18.

Study Procedures

If you agree to participate, you will be asked to …

Participate in one visit lasting about an hour. During this visit, you will complete a series of questionnaires assessing the following:

    - Diabetes self-management: The questions assess parts of self-care including healthy eating, physical activity, blood sugar testing, medication use, foot care, and smoking.
    - Food security: The questions assess how you feel about your food situation.
    - General stress: The questions assess stress as well as feelings of depression and anxiety.
    - Diabetes-related distress: The questions assess fear, depressed mood, demands of living with diabetes, and concerns about the future.
    - Diabetes knowledge: The questions assess facts that you know about diabetes care.
    - Diabetes attitude: The questions assess how important you think it is to keep tight control of your blood sugar.
- Give permission for us to use information from your medical record as part of Athens Nurses Clinic participation.

Risks and Discomforts

Participants may experience discomfort or stress when asked questions about their food situations, stress, or health management. Because sensitive information about food security status, socioeconomic status, physical health, and stress/depression will be collected, participants may also worry about a breach of confidentiality. Proper measures will be taken to keep the individually identifiable information confidential, only shared with the researchers listed in this IRB application, and only used for the purposes of this research project. If any of the questions make you feel uncomfortable, you are not required to answer them.

Benefits

There are no direct benefits of participation in this study. Participating in this study will provide no added benefit to the services you personally receive at the clinic. However, the findings of this study could help better understand how limited access to affordable, healthy food as well as diabetes knowledge and attitude affect the management of diabetes in low-income women with dependents. These findings can help serve as a point from which nutrition intervention programs targeted to low-income women with dependents can be developed to improve diabetes management.

Incentives for Participation

You will receive a free diabetic-friendly cookbook and a $10 grocery store gift card for your participation in this study at the end of your interview.

Privacy/Confidentiality

The data we collect from you will be labeled using a code to indirectly identify you rather than using your name and contact information. The key to the code, which will hold identifying information, will be in a password-protected file on a computer. The project's research records may be reviewed by the research team and by the departments at the University of Georgia responsible for regulatory and research oversight. We will hold on to this information for 4 years or until the study is completed and findings are published.

Taking part is voluntary

Participation in this study is completely voluntary, and you may choose not to participate or to withdraw from the study at any time without penalty. If you choose not to consent to this study, the quality of services you receive from the clinic will not be affected in any way.
If you decide to withdraw from the study, the information that can be identified as yours will be kept as part of the study and may continue to be analyzed, unless you make a written request to remove, return, or destroy the information.

If you have questions

The main researchers conducting this study are Dr. Jung Sun Lee, an associate professor, and Rachel Laudel, a graduate student at the University of Georgia. Please ask any questions you have now. If you have questions later, you may contact Rachel Laudel at laudel@uga.edu or at 404.561.2763. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

Research Subject's Consent to Participate in Research:

To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form and have had all of your questions answered.

_____	_____	_____
Name of Researcher	Signature	Date

_____	_____	_____
Name of Participant	Signature	Date

Please sign both copies. Keep one and return one to the researcher.

APPENDIX D

HIPPA AUTHORIZATION FORM

Authorization to Use and Disclose Protected Health Information for Research Purposes

The HIPAA privacy law (Health Insurance Portability & Accountability), protects your health information. You are being asked to sign this agreement so that researchers may use or disclose your protected health information for research purposes in the study entitled "Factors Associated with Diabetes Management in Low-Income Female Caregivers: A Feasibility Study" which is being conducted by principle investigator, Dr. Jung Sun Lee and co-investigators, Rachel Laudel and Claudette Bailey. Participation in the research is voluntary. If you choose to participate in the research, you must sign this form so that your health information may be used for the research. Your decision to release or not to release this information will not affect the current or future services you receive from the Athens Nurses Clinic. If you do not agree to this, you will not be able to participate in this study.

You authorize Athens Nurses Clinic to disclose your record of race/ethnicity, income, education, family structure, parity, medical history, health insurance, HbA1c records, and food diary records. The researchers will protect this information by using it only as permitted by you in this Authorization and as directed by state and federal laws. If you have any questions and/or wish to revoke this Authorization in writing at any time, you can contact Dr. Jung Sun Lee at the Department of Foods and Nutrition, The University of Georgia, Athens, GA, 30602, 706-542-6783. This Authorization expires at the end of the research study. You have a right to request to see your health information. However, to ensure the scientific integrity of the research, you will not be able to review the research information until after the research protocol has been completed.

By signing below, you give permission for Athens Nurses Clinic, to release your record of race/ethnicity, income, education, family structure, parity, medical history, and HbA1c records to Dr. Jung Sun Lee, Rachel Laudel, and Claudette Bailey for the above-titled research project. You will sign two copies of this form. You understand that you are agreeing by your signature on this form to allow the release of the information stated above. You will receive a signed copy of this authorization form for your records.

_____	_____	_____
Signature of Participant	Printed Name of Participant	Date

_____

Participant Address and Phone

_____	_____	_____
Signature of Investigator	Printed Name of Investigator	Date

For questions or problems about your rights as a research participant, please call or write: The Chairperson, Institutional Review Board, University of Georgia, 609 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu.

APPENDIX E

INFORMED CONSENT AND QUESTIONNAIRE SCRIPT

Script: Obtainment of Consent and Administration of Questionnaires

Below is a script to help guide you through the process of obtaining consent and administering questionnaires. Please familiarize yourself with the participant materials (consent form and questionnaires). You do not have to follow the script verbatim, however, please use this script as a guide as you take the participant through each process.

Order of process:
Informed consent
HIPPA authorization
Questionnaires

1. Obtaining Consent

[Guide participant through each section of the consent form, summarizing each section.]

Thank you for your interest in our research study. Before we get started, I need to tell you a little about the study.

This study is looking at factors that might be associated with the management of type 2 diabetes. We are particularly interested in how limited access to affordable, healthy foods affects diabetes management. We are looking specifically at low-income female caregivers because we want to assess how the burden of supporting dependents affects the relationship between food insecurity and diabetes management. Also, we are investigating how different levels of knowledge about diabetes affect diabetes management and what other factors, like attitude towards diabetes, might influence that relationship.

As a participant, you will be asked to provide about an hour of your time today at the clinic to complete a series of questionnaires and diet recall. The short questionnaires include questions assessing diabetes management, food security status, general stress, diabetes-related distress, diabetes knowledge, and attitude towards diabetes.

In addition to this one-hour visit, we ask that you give us permission to access your medical records as part of Athens Nurses Clinic participation.

You may experience minimal discomfort due to the content of the questionnaires. Please be assured that all of the information you share with us is completely confidential, and we will de-identify all information that can be linked back to you.

Participation is completely voluntary. The decision you make will have no impact on the quality of care you receive at Athens Nurses Clinic.

Please take a couple minutes to look over this consent form. Let me know if you have any questions as you read through the form.

[Answer any question the participant may have.]

By signing this form, you agree that you have read the entire document and understand your role as a participant.

2. HIPPA Authorization

This form explains our desire to use information from your medical record for research purposes. If you agree to release information from your medical record to us, all information will be de-identified and held in confidentiality so that it cannot be linked back to you.

Please review this form and sign at the bottom if you authorize our use of your health information.

3. Administration of Questionnaires

[Each questionnaire includes a separate description of the instructions. Each questionnaire provides a scale of response options.]

Now, I will ask you questions from the questionnaire. The instructions are a little different for each section, so I will explain them to you as we go. If you would like me to clarify any of the instructions or questions, please let me know.

APPENDIX F

QUESTIONNAIRES

Additional Questions

1. What is the highest degree or level of education you have completed?
    a. Less than high school
    b. High school graduate or equivalent
    c. Some college, no degree
    d. Associate's degree
    e. Bachelor's degree
    f. Graduate degree

2. Number of dependents 1 2 3 4 5

	Relationship (child, grandchild, niece, nephew, cousin, etc)	Age	Primary Caregiver? (Y or N)
Dependent 1			
Dependent 2			
Dependent 3			
Dependent 4			
Dependent 5			

3. [*If any dependents 18+ years old*] Does your adult child dependent contribute to household income?

Yes No

Diabetes Self-Management Assessment

I am now going to ask you some questions 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 when you were not sick.

Diet	**Number of Days**
1. On average, over the past month, how many days per week have you followed your eating plan?	
2. On how many of the last seven days did you eat five or more servings of fruits and vegetables?	
3. On how many of the last seven days did you eat high fat foods such as red meat or full-fat dairy products?	
4. On how many of the last seven days did you space carbohydrates evenly through the day?	
5. On how many of the last seven days have you followed a healthful eating plan?	
Exercise	
1. On how many of the last seven days did you participate in at least 30 minutes of physical activity?	
2. 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	
1. On how many of the last seven days did you test your blood sugar?	
2. 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	
1. On how many of the last seven days did you check your feet?	
2. On how many of the last seven days did you inspect the inside of your shoes?	

Adapted from the Summary of Diabetes Self-Care Activities, Toobert et al., 2000

Food Security Assessment

These next questions are about the food eaten in your household in the last 12 months, since (current month) of last year, and whether you were able to afford the food you need.
Note to interviewer: Do not present "don't know" or "refused" as response options; only mark these options if volunteered.

I'm going to read you some statements that people have made about their food situation. For these statements, please tell me whether the statement was <u>often</u> true, <u>sometimes</u> true, or <u>never</u> true for (you/your household) in the last 12 months—that is, since last (name of current month).

HH3. The first statement is, "The food that (I/we) bought just didn't last, and (I/we) didn't have money to get more." Was that <u>often</u>, <u>sometimes</u>, or <u>never</u> true for (you/your household) in the last 12 months?

[ ] Often true
[ ] Sometimes true
[ ] Never true
[ ] Don't know or Refused

HH4. "(I/we) couldn't afford to eat balanced meals." Was that <u>often</u>, <u>sometimes</u>, or <u>never</u> true for (you/your household) in the last 12 months?

[ ] Often true
[ ] Sometimes true
[ ] Never true
[ ] Don't know or Refused

Now, I'm going to ask you some questions about the food situation in your household.

AD1. In the last 12 months, since last (name of current month), did (you/you or other adults in your household) ever cut the size of your meals or skip meals because there wasn't enough money for food?

[ ] Yes
[ ] No (Skip AD1a)
[ ] Don't know (Skip AD1a)

AD1a. [IF YES ABOVE, ASK] How often did this happen—almost every month, some months but not every month, or in only 1 or 2 months?

[ ] Almost every month
[ ] Some months but not every month
[ ] Only 1 or 2 months
[ ] Don't know

AD2. In the last 12 months, did you ever eat less than you felt you should because there wasn't enough money for food?

[ ] Yes
[ ] No
[ ] Don't know

AD3. In the last 12 months, were you ever hungry but didn't eat because there wasn't enough money for food?

[ ] Yes
[ ] No
[ ] Don't know

Adapted from the USDA's U.S. Household Food Security Survey Module: Six-Item Short Form, September 2012

Depression Anxiety Stress Assessment

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:
0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

Diabetes-Related Distress Assessment

Now, I'm going to read you a few issues that some people with diabetes experience. For each one, please tell me to what extent that issue is a problem for you on a scale of 0 to 4, where 0 is not a problem, 1 is a minor problem, 2 is a moderate problem, 3 is a somewhat serious problem, and 4 is a serious problem.

	Not a problem	Minor problem	Moderate problem	Somewhat serious problem	Serious problem
1. Feeling scared when you think about living with diabetes	0	1	2	3	4
2. Feeling depressed when you think about living with diabetes	0	1	2	3	4
3. Worrying about the future and the possibility of serious complications	0	1	2	3	4
4. Feeling that diabetes is taking up too much of your mental and physical energy every day	0	1	2	3	4
5. Coping with complications of diabetes	0	1	2	3	4