THE EFFECTS OF CENTERING IN CARE ON SELF-MANAGEMENT OF TYPE II DIABETES

IN MEDICALLY UNDERSERVED CO-RESIDING ADULTS

by

CAROLYNN ANNE DESANDRE

(Under the Direction of Charlotte Wallinga)

ABSTRACT

Guided by Critical, Humanistic, and Social Support theories this mixed methods study uses the tenets of Hermeneutic Phenomenology and quantitative data trends to illuminate the lived experience of medically underserved co-residing adults living with diabetes. In addition the researcher evaluates the impact of a novel approach to healthcare, the Centering in Care model, on self-management of diabetes in medically underserved co-residing adults. Overarching research questions include the following: (1) What is the day-today lived experience of medically underserved adults living with type II diabetes mellitus?; (2) How does participation in group care health visits affect health locus of control in medically underserved co-residing adults living with type II diabetes mellitus?; (3) What are the effects on self-management of diabetes in medically underserved co-residing adults who participate in a group care model for health visits and education?; (4) How does having a partner participate in group care impact co-residing adults' ability to self-manage diabetes outside the care environment?; (5) What is the relation between health locus of control and physical weight, body mass index, Hemoglobin A1c, and waist circumference? The final study yielded 10 study participants (5

medically underserved co-residing adult pairs). Participants were interviewed both pre- and post-participation in six group care meetings designed to address the key diabetes education topics designated by the American Diabetes Association. Thematic analyses were performed on both pre- and post-participation interview data and researcher field notes collected throughout the study. Following thematic analyses, quantitative data were analyzed using SPSS program to elicit descriptive statistical data, and data trends were compared with qualitative themes for congruency. Findings support previous research which suggests that medically underserved populations can be very successful at self-management of diabetes when methods of delivering care and education are tailored to meet client and family needs. In addition, group care provides an effective means for delivering care to medically underserved families to improve self-management of diabetes.

INDEX WORDS: Diabetes, Medically Underserved, Group Care, Mixed Methods, Phenomenology

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DEDICATION

"If I have seen further than others, it is by standing upon the shoulders of giants."

- Isaac Newton

Undertaking a dissertation is a great feat, and I could not have accomplished this project without the guidance and support of amazing people. I have been fortunate to stand on the shoulders of many giants through this process, and as a result I have seen more clearly the power of research and its impact on our world.

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CHAPTER 1

INTRODUCTION

A Day in the Life of Adult Onset Diabetes

The alarm goes off and John awakes. He rubs his eyes as he begins towards his

bathroom. He opens the case that holds his blood sugar monitor and turns on the machine. He

opens the canister to remove a test strip and finds it empty. John remembers a similar morning

about a week ago when he realized his test strips were getting low, but when you don't have a

regular job and finances are tight sometimes the choices between buying test strips to check your

blood sugar and food to feed your family are complex. No matter which decision you choose

somebody loses. For John the decision is simple. He has been doing a good job with his blood

sugar over the last couple of months. He can tell because he has not had any more episodes like

the one that caused him to visit the emergency room (ER) about three months ago. So, last week

he used the $20 that was for a canister of new test strips to buy groceries for his family.

Three months ago John had a real scare. He woke up one morning very sick to his

stomach with blurry vision. He was sweating and having difficulty breathing and when his wife

Mary was talking to him she sounded like he was listening to her voice in a tunnel. He also had

a lot of numbness and tingling in his swollen feet and hands. Mary insisted they go to the

emergency room, and since John had never felt this way before he agreed. When they got to the

ER a receptionist asked John how he planned on paying for his visit today. Shamefully, John

told the receptionist that he did not have insurance and no regular income because he had been

unemployed for the last six months. The receptionist explained to John that the ER was not a

"free clinic," but since he was showing signs consistent with a life-threatening emergency they

would not turn him away. John and Mary were escorted to a room and within a few minutes a doctor came in to examine John. Following his examination and some tests, the doctor explained to John that his blood sugar was very high, and this was the cause of the way he was feeling. They gave John some medicine in the ER to correct the problem, and when John was feeling better the physician came back in to talk to him and Mary. He explained to John that the test revealed that John was not managing his blood sugar very well, and if he did not want to die or have his feet amputated, John was going to have to do a much better job of losing weight, eating more fresh fruits and vegetables, checking his blood sugar daily, seeing a health professional regularly, and taking his medications as instructed. The physician told John and Mary that if John did not change his behaviors he would continue to be a burden on his family and the ER.

John and Mary left the ER feeling very frustrated. John understood what diabetes was – a problem with the amount of sugar in his blood. He also knew the consequences of diabetes – his whole family had developed diabetes for generations back. He had grown up watching his mother and father, aunts and uncles, and grandparents have strokes, experience pain, have limbs removed and eventually die from some complication of diabetes. Diabetes was a natural process of aging in John's family, and not one he could avoid. John and Mary both agreed with the doctor's advice, but how do you follow those instructions when money is limited and access to healthcare unavailable? After all, it wasn't that John was purposely choosing to ignore the recommendations. He was doing the best he could given his situation. His support through diabetes was Mary and his family, and they knew about as much about diabetes as John did.

Prior to his unemployment John had medical insurance. He saw a healthcare provider annually and was able to afford the medications and blood glucose monitoring supplies to keep

his blood sugar under control, but now his access is limited. This is unfamiliar territory for John and his family, and it both frightens and frustrates Mary and John.

The Problem Statement

Diabetes is a chronic condition affects 25 million people in the United States (Diabetes Statistics - American Diabetes Association, n.d.). Despite evolving technology and increased awareness of the complications of diabetes, the rate of adults developing diabetes continues to increase in the United States (CDC - Diabetes Statistics and Research - Diabetes & Me - Diabetes DDT, n.d.). Without new methods and ideologies for diabetes care and education, it is predicted that by 2020 half of all Americans will be diagnosed with diabetes (Diabetes Data and Trends - CDC, n.d.). Medically underserved adults are at particularly high risk for developing complications from diabetes due to their lack of access to consistent health care and education.

Professional Significance of the Study

Currently in the United States there are approximately 25 million people suffering with diabetes, and about 25% of them are undiagnosed (Diabetes Data and Trends - CDC, n.d.). Diabetes is the seventh leading cause of death in the United States and each year over 200,000 people die from a diabetes-related illness. In addition, there are over 44 million people without health insurance benefits (Diabetes Data and Trends - CDC, n.d.). Lack of health care funds results in medically underserved populations, and in the face of a chronic disease like diabetes, lack of access to healthcare can be fatal.

Approximately 1.9 million people over the age of 20 were newly diagnosed with diabetes in 2010 (Diabetes Data and Trends - CDC, n.d.). According to the Center for Disease Control,

> The estimated economic cost of diabetes in 2007 was $174 billion. Of this amount, $116 billion was due to direct medical costs and $58 billion due to indirect costs such as lost workdays, restricted activity, and disability due to diabetes. People with diagnosed diabetes incur average expenditures of $11,744

per year, of which $6,649 is attributed to diabetes. People with diagnosed diabetes, on average, have medical expenditures that are approximately 2.3 times higher than what expenditures would be in the absence of diabetes. Approximately $1 of $5 health care dollars in the United States is spent caring for someone with diagnosed diabetes, while approximately $1 of $10 health care dollars is attributed to diabetes. (Diabetes Data and Trends - CDC, n.d., para. 1)

In 2011, the United States spent $465 billion on diabetes research, prevention and education; however, the number of individuals diagnosed with diabetes grew at a two-thirds higher rate than any other chronic illness (Diabetes Priorities, n.d.)

Background of the Study

There are numerous societal and professional developments which influenced the conceptualization and development of this study. Currently the US is experiencing a healthcare crisis. Each year the US spends and average of $7,290 per capita on healthcare (OECD Health Data 2013, n.d.). This is an average of $3,000 - $6,000 more than any other industrialized nation worldwide. Despite being the largest spender, the US continues to have one of the lowest life expectancy rates, 78 years (OECD Health Data 2013, n.d.). There are many reasons for this imbalance between money spent and overall health which include rising costs of healthcare, lack of access to care, and failure to adequately treat at-risk populations. In 2011, the US was at the top of industrialized countries with healthcare delivery issues which included 27 percent of Americans unable to pay medical bills in the past year, compared to from 1 to 14 percent in other countries, and 42 percent skipping doctors' visits, recommended care, or not filling prescriptions (Schoen et al., 2011).

Health insurance premiums in the US increased by more than 50% in 2011 which contributed to 17.4% of Americans being medically uninsured (More Americans Uninsured in 2011, n.d.). Despite the billions of dollars invested annually in research and prevention, diabetes

continues to grow at an alarming rate in medically underserved populations in this country

(Diabetes Data and Trends - CDC, n.d.). Innovative methods for reaching medically

underserved individuals and delivering healthcare and information that can foster better self-

management skills is needed. This research study used a unique model of health care, the

Centering in Care model, to deliver diabetes care and education to medically underserved adults

living with type II diabetes and a co-residing adult partner. The goal of this study was to

examine how the implementation of a group care model impacts health locus of control and

ability to self-manage diabetes outside of the health care environment in medically underserved

co-residing adults (MUCA). For clarity in understanding, a glossary is included in Appendix A

which defines all terminology used in this study.

<div align="center">Overarching Paradigm</div>

This study was conducted in conjunction with an advocacy/participatory world view.

According to Creswell (2012), advocacy/participatory research includes an action agenda which

results in reform which may change participant lives or the environment in which participants

live and work. This type of research gives voice to marginalized populations in an attempt to

free them from the constraints which limit their abilities such as language, procedures, and

distributions of power.

<div align="center">Theoretical Underpinnings</div>

The major theoretical underpinning of this study is critical theory. Critical theory

proposes that certain populations of humans are marginalized, such as those of lower

socioeconomic status. This theory seeks to examine those societal hurdles which prevent

individuals from transcending constraints place on them (Creswell, 2012). For medically

underserved and uninsured individuals, access to care is limited. Research indicates that

medically underserved and uninsured individuals generally do not receive appropriate primary care services, and as a result generally experience more chronic diseases which increase their morbidity and mortality (Brown & Marfell, 2005; Duffy, 2008; Weitz, Freund, & Wright, 2001). This study used critical theory to hear through participants' own voices the barriers which make self-management of diabetes challenging when they are medically underserved.

According to Maxwell (2012), "a useful theory illuminates what you see," (p. 43). A critical theory lens permits interpretation of participant's meanings and highlights social and economic problems of medically underserved adults with diabetes. Theoretically, a novel method of delivering care, group care, can empower participants and increase self-management skills in medically underserved co-residing adults with diabetes.

Humanistic theory and specifically Social Learning Theory were overarching influences in this study. In conjunction with research by Julian Rotter (1954) and Carol Rogers (1996) this study embraced the theory that learning is a natural process in which the learner interacts with his/her environment, and learning occurs as a result of that interaction. The locus of control of learning then resides within the learner as opposed to a "teacher" in a more traditional "sage on the stage" learning style (McEwen & Wills, 2014). In humanistic and social learning theories the learner is self-directed, and the assumption is that an educated person knows how to learn and adapt to changing circumstances while continually seeking knowledge (McEwen & Wills, 2014). Group care models are based on this assumption. They acknowledge that patients are knowledgeable about their health conditions, and use of these models empowers patients to direct their healthcare with the provider serving in a facilitator role (Jeanfreau, 2008).

Research Questions

My interest in this study stemmed from a desire to improve diabetes healthcare for the medically underserved families in north Georgia. As illustrated above, diabetes continues to grow at an alarming rate in the US despite billions of dollars invested annually in diabetes research and development. In Georgia, diabetes is the sixth leading cause of death, and in north Georgia approximately 25% of people died from diabetes from 2003-2010 (Diabetes Data and Trends - CDC, n.d.). Researchers suggest that without new modalities of reaching medically underserved populations, diabetes will continue to grow at an alarming rate (Diabetes Data and Trends - CDC, n.d.).

In my own personal experience serving at the Appalachian Nurse Practitioner Clinic, approximately 85% of clients have a diagnosis of diabetes mellitus, and many of them do not have their diabetes well-controlled. It is not uncommon for these patients to miss appointments, run out of medications, and not adhere to dietary guidelines which help to improve glycemic control. In the larger healthcare arena these individuals would be labeled as non-compliant, but non-compliance assumes a person has the means to adhere to medical advice. My focus in this study is to uncover the constraints that medically underserved adults face which prevent them from being compliant with medical treatment plans. Also, by using a novel approach to delivering health education and care to these individuals, I hope to increase self-management skills to better maintain diabetes control outside of the healthcare setting. The following research questions guided this study:

1. What is the day-to-day lived experience of medically underserved adults living with type II diabetes mellitus?

2. How does participation in group care health visits affect health locus of control in medically underserved co-residing adults (MUCA) living with type II diabetes mellitus?

3. What are the effects on self-management of diabetes in co-residing adults who participate in a group care model for health visits and education?

4. How does having a partner participate in group care impact co-residing adults' ability to self-manage diabetes outside of the care environment?

5. What is the relation between health locus of control and physical weight, body mass index, waist circumference, and Hemoglobin A1C?

<div align="center">Subjectivity Statement</div>

Nursing philosophy originated in the early 1800s with the work of Florence Nightingale (Nightingale & McDonald, 2001). Nightingale was the first nurse to record notes on the care and healing of patients, and through these writings she developed philosophies of health promotion and wellness. Nightingale was specifically concerned with the public health of the poor. According to Nightingale,

> The state of the dwellings of the poor, the sanitary or rather unsanitary state of London in general, is not often taken into account in the ill health it produces, e.g. consumption, weakness of intellect, rheumatism. We only think of the violent and sudden deaths of typhus and cholera. Yet the poor cannot drain their own streets, nor reform their own dwellings. Those who come from the worst dwellings are always the most sickly. (Nightingale & McDonald, 2001, p. 7)

Nightingale worked tirelessly developing her theories of holistic nursing – caring for individuals with consideration not only to their physical ailments but also tending to their psychological health, their environment, and their social support system. She is considered to be

the first nurse researcher by many, as much of her work stemmed from observation, intervention, and careful data collection and evaluation of patient response to treatment. "Nightingale believed that the nurse's function was to put the patient in the best possible situation for nature to act on him or her, projecting the idea that nursing is based on knowledge of people and their surroundings" (Johnson & Webber, 2015, p. 134). Nightingale's philosophy of health continues to serve as a pillar of nursing education, and nursing as a profession supports the idea of holistic care individualized to specific patient needs.

I learned about Nightingale in the early 1990s and in 1993 began working as an open heart transplant surgery and cardiac critical care unit nurse at a hospital in mid-town Atlanta. As a new nurse I strived to uphold the philosophies of Florence Nightingale that had been tattooed on my brain from nursing school – think holistically. Even in the surgery room and recovery unit I was concerned with lighting, noise, and patient and family comfort. I went to great lengths to learn about my patients and their families to be able to relate to them as human beings and not just patients on whom to complete the technical duties of my job such as monitoring vital signs and giving medications. I realized early on in my career that this aspect of holistic caring is what called me to nursing; it stemmed from my heart – a true desire to learn others stories so that I could tailor the care I delivered to meet their needs.

As the economic environment changed so did my ability to deliver holistic care. About one year after I began working in cardiology, the hospital pushed nurses to complete more tasks in their allotted work time and get patients out the door sooner after surgery. This practice resulted in less time at the bedside and less time to learn patient stories. In 1995, I changed hospitals and went to work in a different area of patient care – labor and delivery. I chose this area because nurses who worked there were still spending a majority of the time at the patient bedside.

Working as a labor and delivery nurse afforded me the opportunity to go back to learning patient stories and working with families. Soon after I started working as a labor and delivery nurse, I returned for my master's degree in nursing with certification as a nurse-midwife and family nurse practitioner. Returning to school for an advanced practice degree provided me with the advanced skills and knowledge to continue to work hand-in-hand with my patients and their families.

In 2007, I was afforded the opportunity to teach at the University of North Georgia in the Master of Science/Family Nurse Practitioner program. Along with the faculty position I was given a part-time nurse practitioner position at the Appalachian Nurse Practitioner Clinic (ANPC), a federally funded rescue clinic for medically underserved and uninsured residents of north Georgia. This was the first time I had ever worked with medically underserved families. Medically underserved individuals present unique challenges to providers in a primary care setting. According to Hooker (2013),

> Their rates of obesity and cardiovascular and pulmonary disease, coupled with learning difficulties and poor quality of life, create a ladder with widely spaced and slippery rungs. The diseases borne by socially disadvantaged groups do not create a compelling medical practice for everyone, as compliance remains low and treatment failure rates are high. (p. 339)

My first year working in this clinic was filled with heroic attempts to care for these individuals, spending long hours educating patients and allocating resources for them, such as drug assistance programs for prescription medications and discounted or pro bono referrals to specialists. My work was creative and incorporated innovative methods for treatment because health care is expensive, and patients with limited resources often can not afford the treatments necessary to keep them healthy. I believed if I could educate these individuals and get resources for them, they in turn could improve their health.

The reality of my initial months of working with the ANPC patients with diabetes was a much different story. Initially I would spend hours with patients teaching them about diabetes and using colorful instructional brochures produced by drug companies and professional organizations to help solidify what I was telling patients to do. I would then see the patients back for follow-up visits and much to my surprise, their blood glucose and lab values would be worse than when I first met them. I became confused about why this was happening. After about six months of practice I began to question my patients about why they thought their health was not improving. Initially I did not get much response, and then one day a particularly outspoken patient who was seeing me on a regular basis asked me if I really wanted to know what she thought about the situation. When I told her yes, she instructed me to sit down and take the laptop computer out of my hands and listen to her. I spent the next 45 minutes listening to her describe her experiences with me. She very honestly told me that my white lab coat and my medical "speak" did not make me an expert on her diabetes. She said that although she appreciated all of the brochures I gave her, none of them were applicable to her life, thus they were useless. She explained to me that it frustrated her that when she filled out an application to get medicine that was too expensive for her to pay for, it took almost two months before she received the medicine, and she particularly despised the fact that I always walked in the room with the laptop computer in my hand and typed information into it the whole time I spoke with her. She told me that although she respected my education, she knew more about diabetes' effects on her body than I did. After all she was the person living with the disease, not me.

I had an epiphany. Maybe the reason my patients were not successful in self-managing their diabetes was because my approach did not fit their reality. Although I had adequate resources, patients could not use them because the resources did not fit patients' realities of living with

diabetes. I began to research how to change my approach. I changed my business clothes, wearing more comfortable semi-professional street clothes to the clinic, and I lost the prized white lab coat. When I entered a patient's room, I immediately put the laptop down on the counter, sat down on the stool at equal or lower physical level than the patient, and asked the patient about their thoughts on how things were going with their diabetes.

It was amazing the difference my approach made. Patients told me things I had not been able to uncover for months. I began to learn about their stories and their beliefs about diabetes. One of the most interesting things I learned was that my patients with diabetes did not see it as something that was preventable. They talked about generations of family members afflicted with diabetes and how it was something that if you lived long enough you were just going to get.

These conversations with patients changed my professional life. I began to believe that maybe diabetes would be less of a financial drain on the US if we focused less on developing new tools for diabetes management and education and simply tailor existent tools to meet our patient needs. I spent the next four years in north Georgia exploring new ways to provide healthcare and education to my medically underserved patients with diabetes. I also participated in ongoing continuing education in diabetes care. According to Li, Williams, and Scammon (1995), health professionals committed to working with medically underserved populations have a strong commitment to serve humanity and make a difference. They thrive on creatively seeking ways to meet complex individual needs within an environment of limited resources. I felt this commitment, and it became my motivation to engage in this study. According to Grbich (1999) emotional intersubjectivity is an important aspect of understanding the meanings of others. "Emotional intersubjectivity requires us to enter the world of the researched and bring

their experiences into our own frames of reference through the process of sharing," (Grbich, 1999, p. 67).

As I continued my quest for new and innovative methods to help my patients, I began reading about a new method in delivering care – group care. I was initially exposed to group care in 1998, while studying for my midwifery certification. I participated in clinical education at Grady Health Clinic where they used group care to deliver prenatal care to medically underserved pregnant women at high-risk for pre-term birth and/or low-birth weight babies. I witnessed how women who participated in the group care shared openly about their experiences with pregnancy as they discussed issues such as weight gain, body image, plans for labor, and caring for baby at home. I watched women take accountability for their health as they weighed themselves and took their own blood pressures and recorded this information in a log for the midwife who facilitated the group. The meeting was social. There were refreshments served, and music played in the background. The meeting was held in a circle with everyone facing each other, including myself and the facilitating midwife.

I decided to review the research on group care and found that group prenatal care resulted better outcomes for mothers and babies including: fewer pre-term births, fewer low-birth weight babies, and higher self-esteem in mothers (Ickovics et al., 2007; Rising, 1998). I began to question if group care could work for pregnant women, then maybe it could work for medically underserved patients with chronic diseases like diabetes.

I then turned my focus to searching for literature on the use of group care models in the treatment of chronic disease. I found the literature relatively sparse on the use of group care models in the management of chronic disease, specifically diabetes. As discussed in the literature review in the next chapter, I found a few studies which highlighted the effects of group

care on patient education and self-management; however, most of these studies focused using group care models with individuals diagnosed with chronic disease (Clancy, Huang, Okonofua, Yeager, & Magruder, 2007; Davis, Sawyer, & Vinci, 2008; Partiprajak, Hanucharurnkul, Piaseu, Brooten, & Nityasuddhi, 2011; Pick, 2009). I could not find any literature using a group care model approach to educate and treat families living with diabetes. I then decided to contact Sharon Rising, CEO of the Centering in Healthcare Institute, one of the leading organizations in developing and training healthcare professionals to deliver group care. During our conversation Ms. Rising informed me that several institutions were currently investigating the use of group care to deliver care to patients with hypertension, Alzheimer's disease, and diabetes, but she was not aware of anyone using the Centering in Care Model to deliver care to families living with diabetes. She was very interested in my ideas for my research study and suggested I attend a training certification seminar for Centering in Care facilitation. In April 2013, I trained in facilitating care via the Centering in Care Model. I attended a two-day Centering in Care Facilitator Workshop and was certified as a Centering in Care facilitator. This certification permitted me to conduct group care visits via the Centering in Care model.

One of my main interests in conducting a study with medically underserved adults living with diabetes was to learn the "truths" of their lived experiences. Social research seeks to discover, understand, and communicate the "truth" of a situation (Grbich, 1999). For my study, once the "truth" was uncovered, new methods for delivering care and encouraging self-management were employed to improve overall health in medically underserved individuals with diabetes. Additionally I sought to evaluate the effectiveness of using Centering in Care to improve self-management in medically underserved adults living with diabetes. To fully evaluate the effectiveness of this method of delivering care I needed to evaluate multiple aspects

of Centering in Care including participant thoughts and feelings about group care and changes in health indicators such as weight and blood sugar readings.

<div align="center">Rationale for a Mixed Methods Design</div>

According to Vogt, Gardner, and Haeffele (2012), combination research designs are used when research questions are complex or have multiple parts. A mixed methods approach permitted a variety of data to interpret and formulate a complete picture of the impact of diabetes on medically underserved adults. Both qualitative and quantitative data served to create a full story of diabetes in medically underserved co-residing adults (MUCA). Two reasons to use a combination research design are (1) when you want to elaborate, clarify, or build on findings from other methods and (2) when you want to tell the full story in an area of inquiry (Vogt et al., 2012).   This study sought not only to provide a complete story of the experience of diabetes in medically underserved families, but to also examine the effectiveness of a new model of health delivery in improving self-management skills in MUCAs.

CHAPTER 2

REVIEW OF THE LITERATURE

Definition and Prevalence of Diabetes

Diabetes is defined as, "a group of metabolic diseases characterized by hyperglycemia

resulting from defects in insulin secretion, insulin action, or both. The chronic hyperglycemia of

diabetes is associated with long-term damage, dysfunction, and failure of various organs,

especially the eyes, kidneys, nerves, heart, and blood vessels" (Diagnosis and Classification of

Diabetes Mellitus, 2004, p. S8). There are two major categories of diabetes. In Table 1 the

categories, diagnostic criteria, and incidence are listed for each diabetes category.

Table 2.1
Categories of Diabetes Mellitus with Diagnostic Criteria and Incidence

Diabetes Category	Diagnostic Criteria	Incidence
Type I	Also known as juvenile-onset diabetes. Beta cell destruction resulting in absolute insulin deficiency. Etiology is often a cellular-mediated autoimmune destruction of the beta cells (β-cells) of the pancreas.	5-10% of population with diabetes
Type II	Also known as adult-onset diabetes. Insulin resistance with relative insulin deficiency or insulin secretory defect with insulin resistance. Etiology can be multifactorial but include obesity; however, autoimmune destruction of β-cells does not occur.	90-95% of population with diabetes

Note: Adapted from "Diagnosis and Classification of Diabetes Mellitus," 2004, *Diabetes Care*, 27.

Due to the complexity of the disease a person with diabetes must be consistently

monitored and educated by a qualified health care professional. In addition, people with diabetes

need access to quality care and a consistent supply of medications necessary to treat the disease

and improve their quality of life.   For most Americans access to healthcare services is provided through either medical insurance or federally funded programs such as Medicare and Medicaid. However, currently in the US one quarter of the population lacks access to healthcare services (Schoen et al., 2011). This population is known as medically underserved or uninsured, and for them, a chronic illness such as diabetes can be lethal.

<div align="center">Challenges in Caring for Medically Underserved with Diabetes</div>

Diabetes in medically underserved populations presents unique challenges for healthcare professionals (Bodenheimer, Wagner, & Grumbach, 2002; Clancy et al., 2007; Davis et al., 2008; Fokkens et al., 2011; Lee et al., 2011; Partiprajak et al., 2011; Philis-Tsimikas & Walker, 2001). Medically underserved individuals do not receive ongoing health surveillance, thus managing a chronic disease like diabetes can be a daunting task. Traditionally, medically underserved individuals were often labeled non-compliant due to their inability to follow recommendations for management of their disease. The underlying assumption is that these individuals are consciously choosing not to manage their diabetes. However, lack of regular access to care and the limits imposed by a lower socioeconomic financial status make it difficult for these populations to afford the necessary tools to effectively treat diabetes. As noted below, results from research studies indicate that medically underserved individuals are often concerned about their health (Alverson & Kessler, 2012; Philis-Tsimikas & Walker, 2001).

Alverson and Kessler (2012) discovered that heart disease and diabetes were major health concerns expressed by medically underserved families. Researchers suggest that with interventions tailored to meet individual and family needs, medically underserved populations can effectively manage and reduce co-morbidity risks associated with diabetes (Garcia-Huidobro, Bittner, Brahm, & Puschel, 2010; Rosal et al., 2011). In a study by Lewin (2005)

family functioning and adherence were strongly correlated with metabolic control in children with diabetes. Based on these findings, the behaviors that characterize a person as non-compliant are not necessarily the result of deliberate choice but may be the result of decisions due to social and economic situations.

Tailoring healthcare education and treatment to clients has been shown to improve health outcomes in medically underserved populations (Davis et al., 2008; Philis-Tsimikas & Walker, 2001). Philis-Tsimikas and Walker (2001) studied culturally tailored diabetes education in a medically underserved Latino population (N=300) and found that patients enrolled in the tailored diabetes education program had significantly improved clinical outcomes which included lower hemoglobin A1c (HbA1c) values and increased compliance with medical treatment. Davis et al. (2008) conducted a randomized control study on improvement of weight and glycemic control in 143 obese medically underserved patients with diabetes. This study utilized a Pounds-Off-With-Empowerment (POWER) program to encourage lifestyle change to improve diabetes control. Findings showed that both weight and glycemic control improved in the treatment group that received literacy appropriate, tailored treatment.

Currently in the US, the Affordable Care Act has been implemented to increase access to healthcare for medically underserved and uninsured populations; however, one of the key issues with implementation of this plan is the lack of healthcare providers to address individual healthcare needs (Adashi, Geiger, & Fine, 2010). As a result, in addition to the creation of more healthcare providers, the US must explore new economical and efficient methods of delivering care. Balancing the economics of healthcare and the specific needs of individuals may prove burdensome for primary care providers. Thus, practitioners must explore practices which provide ongoing support for patients outside the healthcare arena. For medically underserved

individuals with diabetes, identifying avenues of support outside of the primary care setting is essential to glycemic control.

<div align="center">The Role of Family in Diabetes Management</div>

Many studies suggest that the family is the primary social structure by which individuals diagnosed with diabetes learn to cope with their illness (Alverson & Kessler, 2012; Edelstein & Linn, 1985; Safyer et al., 1993; Thompson, Auslander, & White, 2001). In a 1985 study by Edelstein and Linn, 97 men diagnosed with diabetes were surveyed about familial environment. The researchers suggest that relaxed family environments with low levels of familial conflict provide greater support of individuals with diabetes which results in better metabolic control of their disease. Klomegah (2006) surveyed 150 adults with diabetes about their emotional and instrumental familial support which is influential on adherence to dietary regimen. Researchers suggest that while both emotional and instrumental support influence dietary adherence in diabetes, instrumental support of family members participating in the same dietary habits as the person with diabetes was most influential in dietary adherence. These results show that in addition to providing support, the family provides an influential learning environment for health behaviors (Klomegah, 2006).

Much of the traditional research on the impact of diabetes on the family has been conducted on families with children diagnosed with diabetes. Results from these studies indicate that family influence and perception of diabetes is directly related to morbidity and mortality of disease. (Cerreto & Travis, 1984; Safyer et al., 1993; Thompson et al., 2001). In a study by Safyer et al. (1993) researchers found that diabetes adjustment in children is significantly influenced by pubertal development; however, positive familial environment and support improved adherence to diabetes treatment regimens in newly diagnosed adolescents with

diabetes (N = 49 adolescents). According to Safyer et al. (1993), "traditionally adolescence has been described as a period in which family relationships deteriorate and adolescent rebellion, parent-adolescent conflict, and adolescent detachment are normative and desirable" (p. 125). In this study families who were more cohesive and organized in their family activities and responsibilities had adolescents who were more successful in adapting to lifestyle changes necessary with diabetes (Safyer et al., 1993).

Thompson et al. (2001), in their study of 155 children diagnosed with diabetes, found that familial structure is a significant predictor of health when controlling for race, child's age, family socioeconomic status, and adherence. As evidenced in this study, adolescents from single-mother families were in poorer health and had a more difficult time maintaining glycemic control than adolescents in dual parent families. Type 1 diabetes mellitus is a chronic metabolic disorder and is one of the most common chronic diseases in childhood. The study discussed in this In this study researchers examined the extent to which family structure is significantly associated with health in youths with Type 1 diabetes. A convenience sample of 155 children with diabetes and their mothers completed face-to-face interviews; multiple regression analyses were conducted. Findings demonstrated that family structure remains a significant predictor of youths' health when statistically controlling for race, child's age, family socioeconomic status, and adherence. Social workers in outpatient medical settings are in a unique position to develop family-oriented strategies targeting this neglected area of primary care," (Thompson et al., 2001). As demonstrated by the aforementioned studies, intervention strategies for patients with diabetes must include communication with and understanding of the family, as the family serves as a powerful influence and educator of health behaviors that can potentially optimize self-

management of diabetes.   Families are key social learning influences for health beliefs and

behaviors.

<div align="center">Families and Health Locus of Control</div>

One of the greatest challenges for individuals and families coping with a chronic disease

such as diabetes is feeling as if they have the ability to control their disease progression and

treatment. Results from research studies indicate that many patients who do not follow

recommended treatments for diabetes do so because they believe they have no control over the

progression of the disease (Gillibrand & Flynn, 2001; Lowery & DuCette, 1976; O'Connor,

Crabtree, & Abourizk, 1992).

Gillibrand and Flynn (2001) found in their study of adults with diabetes (N = 18) that

people with diabetes felt that the control of their chronic condition was in the hands of health

care professionals responsible for their care, and that individually, they had relatively little

control over their diabetes. O'Hea et al. (2009) report that medically underserved individuals

with diabetes (N=109) who had relatively low self-efficacy scores expressed feelings of little

control over their disease. This resulted in a decreased ability to follow recommended guidelines

and effectively self-manage their diabetes (O'Hea et al., 2009). Results from additional research

literature also suggest that individuals with high internal locus of control are more active

participants in their knowledge and self-care practices with chronic disease (Grotz, Hapke,

Lampert, & Baumeister, 2011; Knappe & Pinquart, 2009; Kostka & Jachimowicz, 2010).

Health locus of control refers to a person's belief of his/her degree of control over his/her

own health status (Schlenk & Hart, 1984). According to early researchers, health locus of

control exists along a dichotomous continuum from internal to external control. External health

locus of control is characterized by an individual who believes that his/her health is controlled by

an outside force such as a healthcare provider or a significant other. Internal health locus of

control refers to the belief that an individual has the ability to control his/her health through

behavior (Wallston & Wallston, 1981).

Locus of control is based on Rotter's Social Learning Theory, which proposes that a

person's potential to engage in a behavior is the product of the person's expectancy that the

behavior will lead to a certain outcome and the person's value of that outcome (Rotter, 1954).

According to this theory, the person's expectancy reflects his/her locus of control and is a fluid

perception across situations (Rotter, 1954). Thus, although locus of control is greatly influenced

by context, it is a perception carried within a person from situation to situation. In Rotter's

theory expectancies, or locus of control, links human behaviors to outcomes (Wallston, 1992).

Rotter's Social Learning Theory. In 1954, Julian B. Rotter, a clinical psychologist,

introduced a social learning theory which incorporated aspects of both learning theory and

personality theory (Rotter, 1954). Rotter's Social Learning Theory was based on the principle

that learning involved more than just cognition. He suggested that learning occurs when an

individual interacts with his/her environment and is dependent on the influence of an individual's

personality (Rotter, 1954). From Rotter's perspective although learned behavior is a very social

endeavor, it is also heavily influenced by individual personality. Since personality is learned

through interaction with others, human behavior is also heavily influenced by an individual's

social environment. There are five basic assumptions in Rotter's Social Learning Theory. In

Table 2 these assumptions are listed along with their descriptions.

Table 2.2
Rotter's Social Learning Theory Assumptions

Assumptions	Descriptions
Humans interact with their meaningful environments	A person's personality represents the interaction of an individual with his/her environment.
Human personality is learned.	Individuals are not inherently born with a personality. Personalities are learned by engaging with the environment and thus they can be changed or modified as people are learning.
Personality has a basic unity	There is some basic level of stability of personality. This indicates that at a basic level individuals retain what is learned and what is valued as a part of their personality.
Motivation to learn is goal-directed	People are naturally drawn forward based on their goals. People learn to move towards those behaviors which serve as reinforcements while moving away from punishments.
People are capable of anticipating events	People are capable of changing their personality and their environment based on learning.

Note: Adapted from *Social Learning and Clinical Psychology*, by James B. Rotter, 1954.

Rotter also suggested that learning is based on four variables within an individual. These four variables are: (1) behavior potential, the possibility of a particular response given time and place in relation to its likely reinforcement; (2) expectancy, a person's confidence that a particular reinforcement will follow a specific behavior pattern given a specific situation; (3) reinforcement value, a person's preference for a particular reinforcement over another reinforcement when both reinforcements are equally likely to occur and is highly dependent on both individual perception (internal value) and society's evaluation of behavior (external value); and (4) psychological situation, the part of the internal and external world to which a person responds (Rotter, 1954).

Using the basic assumptions and variables, Rotter posited that behavior can be predicted, and that predicting behavior is dependent on understanding a person's general expectancies (Rotter, 1954). Rotter stated that general expectancies are dependent on a person's needs, and he defines six categories of needs which are functionally-related categories of behaviors (Rotter, 1954). In Table 3 Rotter's categories of needs and their descriptions are listed.

Table 2.3
Rotter's Categories of Needs and Descriptions

Categories of Needs	Descriptions
Recognition status	The need to achieve, excel, or have others recognize your worth.
Dominance	The need to control behavior of others, to be in charge, or to gain power over others.
Independence	The need to be free of domination of others.
Protection-dependence	The need to have others take care of us and protect us from harm.
Love and affection	The need to be warmly accepted by others and be held in friendly regard.
Physical comfort	The need to secure food, good health, and physical security.

Note: Adapted from *Social Learning and Clinical Psychology*, by James B. Rotter, 1954.

Rotter used a general prediction formula for behavior. According to Rotter's formula, a need potential is the product of a person's freedom of movement and need value, where the need potential is defined as the possible occurrence of a set of functionally related behaviors directed toward the satisfaction of similar goals (Rotter, 1954). In this formula, a person's freedom of movement refers to the overall expectation of being reinforced for performing those behaviors directed at satisfying their goal, and need value reflects the extent to which a person prefers one

set of reinforcements over another. Rotter suggested that the goal of any given behavior is to

achieve harmony between a person's freedom of movement and their need value (Rotter, 1954).

According to Rotter (1990), maladaptive behavior occurs when there is disharmony between

freedom of movement and need value resulting in a persistent behavior that fails to move a

person toward a desired goal.

During the 1980-1990, Rotter expanded on his Social Learning Theory due to ongoing

interest in the fields of psychology and social science of behavior acquisition and control of

reinforcement (Wallston, 1992).   According to Wallston (1992), interest in internal-external

control and expectancy of reinforcement is the result of historical inquiry to causality of human

behavior. This is embedded in the larger theory of social learning. Rotter suggested that future

research in understanding human behavior must not only rely on observables, but must take into

account the complexities of human thought (Wallston, 1992).

Humanistic and social learning theories permeated human sciences during 1960-1990. In

1961, Carl Rogers published *On Becoming a Person*, which explained a client-centered approach

to psychotherapy based on the tenets of humanistic and social learning theories. Rogers' tenets

have been used extensively in teaching and learning where principles of active engagement of

learners influenced the patient-centered movement in healthcare which began in the mid-1960s

and continues to modern day (Heim, 2011). Rogers spawned three decades of research which

supported the idea that individuals respond more favorably to practitioners who take a patient-

centered approach to health education and treatment as this demonstrates empathy which in turn

results in the client feeling accepted (Kirschenbaum & Jourdan, 2005).

In 1988, Alan Rogers proposed that social learning theory does not improve the

biological fitness of a population. The probability that the behavior is adopted and continues is

largely affected by the genetic evolution of the culture (Rogers, 1988). Failure of the culture to adapt to evolution results from a reduction of individual learners due to the spread of social learning. "Through social learning, an individual acquires behavior that was originally acquired by individual learning in some previous generation" (Enquist, Eriksson, & Ghirlanda, 2007, p. 7). In 2007, Enquist, Eriksson, and Ghirlanda suggested a modification in Rogers' theory. Entitled Critical Social Learning, this theory incorporates the fundamental principles of Social Learning Theory and Cognitive Learning Theory by acknowledging the ability of the learner to critically appraise a behavior.

One common theme in the evolution of research on Social Learning Theory is the integration of personal cognition and belief with social influences on human behavior. In a study by Bonetti and Johnston (2008) Social Cognitive Theory and Social Learning Theory were integrated to evaluate the influence of intention and perceived control on walking behaviors of post-stroke patients (N=203). Researchers found that perceived control over anticipated behavior of walking following a stroke was highly influential of stroke recovery. In addition, researchers found that low cognitive belief of perceived control could be improved with psychological treatment. This treatment resulted in improved post-stroke walking behavior (Bonetti & Johnston, 2008).

Social Learning Theory provides a solid framework for studying human response to the development of chronic disease. As suggested by the literature, much of the way humans cope and manage chronic illness depends on how they have observed other members of their social units cope with similar problems (Jacobs-Lawson, Waddell, & Webb, 2011; Lewin, 2005; Lowery & DuCette, 1976; O'Hea et al., 2009; Safyer et al., 1993; Schlenk & Hart, 1984;

Thompson et al., 2001; Trief et al., 2011). Thus, successful chronic disease management such as diabetes, is largely dependent on socially learned behaviors.

Health locus of control. Social Learning Theory was the impetus to Wallston's concept of Health Locus of Control (Wallston, 1992). Health Locus of Control (HLC) was developed in conjunction with the Health Locus of Control Scale (HLCS) in 1976 by Wallston, Wallston, Kaplan, and Maides. Fundamental to the HLCS is the proposition that, "people's perceptions of control over their own health status, regardless of the truth of those perceptions are generally believed to be major determinants not only of their health-related behavior, but, ultimately, of whether they stay healthy or become ill" (Wallston, 1992, p. 184).

Central to the HLCS is that the potential for an individual to engage in a health behavior results from a combination of the degree to which a person's belief that the behavior will influence their health status (internal health locus of control), and the person's value of health (psychological and mental well-being) (Wallston, 1992). The first operationalized HLCS (1976) was an 11-item Likert-scaled questionnaire that measured locus of control on a dichotomous scale - high scores were indicative of an external locus of control and lower scores indicated a more internal locus of control. The original HLCS was tested on undergraduate college students at Vanderbilt University (N = 98) to determine their beliefs about their ability to control their health. This sample was a homogenous population in that all study participants were white college students from middle-class families (Wallston & Wallston, 1981). Participants were scored as either "health-externals," as evidenced by higher scores on externally worded beliefs which indicated individuals believed health was controlled by outside influences, or "health-internals," those who believe that locus of control is internal with health as a result of one's own behavior (Wallston & Wallston, 1981).

In 1978, Wallston, Wallston, and DeVellis modified the HLCS to a more multidimensional measure of health locus of control. This modification was consistent with literature of the 1970s that supported the theory of locus of control influenced by more than just a dichotomy of belief of health resulting from either individual behavior or outside influences over which individuals have no control (Wallston, Wallston, & DeVellis, 1978). The new HLCS included the additional criteria - chance and powerful others. In the new model chance refers to the fate or luck of an individual. Chance is a factor outside of an individual's control. Powerful others are people who individuals believe control their fate (Wallston, 1992). For example, in the case of health locus of control, a powerful other would be an individual's healthcare provider. Both chance and powerful others influence beliefs and behaviors, thus were considered moderators of locus of control (Wallston, 1992). The Multidimensional Health Locus of Control Scale (MHLCS) proposes that an individual's locus of control and health values are more predictive of health behavior outcome than either variable independently (Wallston, 1992). The MHLCS was tested on a more heterogeneous group of adults (N=115), primarily middle class individuals recruited from a Nashville airport (Wallston & Wallston, 1981). In this study, Wallston and Wallston (1981) found consistency among the variables measured by the MHLCS – internal locus of control, chance, and powerful others.

Historically numerous studies have used the MHLCS to evaluate the link between health locus of control and health behavior change (Pender, Walker, Sechrist, & Frank-Stromborg, 1990; Winefield, 1982). In 1982, Winefield conducted a study to evaluate the reliability and validity of the MHLCS. Winefield (1982) found that the internal locus of control and the powerful others variables remained relatively stable; however, the chance variable remained unpredictable and varied over time. It was suggested that individuals be evaluated within the

context of time. In 1987, Affleck, Tennen, Pfeiffer, and Fifield examined patients' perception of control and its effect on adaption to chronic illness over time. As proposed by this study, patients who perceive greater control over their disease state and treatment have a more positive emotional response to chronic illness, and are better able to self-manage their disease over time (Affleck et al., 1987).

More recently Bell, Quandt, Arcury, McDonald, and Vitolin (2002), suggested that the MHLCS results may vary based on ethnicity and demographic difference. In this study older adults (N = 76 adults) were examined, and the researchers found a wide range of variability in the correlation of the MHLCS, health belief, and health promotion behaviors.

Diabetes and locus of control. There are few research studies done on medically underserved families and their beliefs about health in the face of diabetes.   A common theme present in HLC research is the relationship of HLC and quality of life. Researchers propose that an increased HLC promotes self-efficacy and improved quality of life (Knappe & Pinquart, 2009; Kostka & Jachimowicz, 2010).

In a study by O'Hea et al. (2009), 109 low-income individuals with type II diabetes mellitus were administered the MHLCS and findings yielded that individuals with higher MHLCS levels better managed their diabetes as evidenced by hemoglobin A1C levels. Results of this study indicate that patients with diabetes who have a strong internal locus of control are better able to adapt behavior changes to reduce their risks of complications of diabetes as opposed to people who have an external locus of control, such as their family. Interestingly, it was noted that individuals with an external locus of control often also had a low self-efficacy, which is believed to impact their ability to adapt to healthy behaviors in the face of diabetes (O'Hea et al., 2009).

Grotz et al. (2011) found that higher HLC scores were correlated with adequate health behaviors; however, low socioeconomic status was found to be negatively correlated with a high HLC. Philis-Tsimakis and Walker (2001) showed that diabetic clinical management and patient self-management improved in a culturally sensitive intervention program that focused on health literacy and self-management of diabetes in a Latino population. The researchers suggest that we cannot rely on increasing locus of control alone. Practitioners also must employ strategies which are uniquely tailored to meet the needs of the target patient population. Collectively, the findings from Philis-Tsimakis and Walker (2001), O'Hea et al. (2009), and Grotz et al. (2011) indicate that programs addressing HLC in specialty populations can be effective in improving self-management of disease if the programs are tailored to meet the specific needs of lower socioeconomic populations.

Another common theme in HLC in diabetes research is the role of social support and family. In Schlenk and Hart (1984), a convenience sample of 30 adults with diabetes was selected to complete a questionnaire incorporating the MHLCS. Researchers in this study found that the relationship between health locus of control and medical compliance was significantly influenced by social support and influence of powerful others. The variation in study participants' responses to questionnaires suggested that there are numerous factors within individuals and their environments that moderate their perception of locus of control, and this in turn affects an individual's ability to effectively manage their chronic illness (Schlenk & Hart, 1984).

Klomegah (2006) showed that active involvement of family members, friends, and significant others greatly impacted the lives of people with Type II diabetes. It was found that understanding the social environment and inclusion of the family in education and treatment is

key to successful lifestyle adaptation necessary to live optimally with diabetes. Both the Klomegah (2006) and the O'Hea et al. (2009) studies reflect the principles of Rotter's Social Learning Theory: behavior is socially learned and is influenced by both individual personality and human environment (Rotter, 1954).

Other researchers propose that treatment plans which include the patient and family as active participants result in better patient adherence to recommended treatments and lifestyle modifications. Schlenk and Hart (1984) reported social support and powerful others accounted for up to 50% of the variance in patient compliance. Additionally Knappe and Pinquart (2009) suggested that successful aging in an adult population with chronic disease, such as diabetes, was correlated with higher HLC and increased social support. Together the results of these studies indicate that future research in HLC and chronic illness should acknowledge and incorporate social support as an influential factor.

Health Locus of Control incorporates the idea that individuals effectively self-manage diseases over which they feel they have control (Grotz et al., 2011; O'Hea et al., 2009; Schlenk & Hart, 1984); however, Hummer, Vannatta, and Thompson (2011) conducted a meta-analysis of the literature on locus of control and metabolic control of diabetes which suggests no correlation between locus of control and metabolic control of diabetes. While they found a slightly positive correlation between external locus of control (powerful others and chance) and metabolic control of diabetes, they also note that their results are inconclusive (Hummer et al., 2011).

Review of the literature on HLC and diabetes collectively suggests that both internal and external locus of control impact a person's ability to self-mange chronic disease such as diabetes. Interestingly, as suggested in the literature, the degree to which individuals in specialty

populations such as medically underserved are influenced can be modified with healthcare approaches which are tailored to the characteristics of the population (Grotz et al., 2011; Hummer et al., 2011; Knappe & Pinquart, 2009; O'Hea et al., 2009; Philis-Tsimikas & Walker, 2001; Schlenk & Hart, 1984).

Another common theme in HLC research is the propensity of specialty populations to externalize their health locus of control (Gillibrand & Flynn, 2001; O'Hea et al., 2009). In this literature specialty populations are groups of people whose characteristics limit their access to healthcare services and education. Examples of individuals in specialty populations include but are not limited to minorities, low socioeconomic status, limited education achievement, women, and medically uninsured (Gillibrand & Flynn, 2001; O'Hea et al., 2009). By externalizing locus of control, specialty populations such as medically underserved are more vulnerable to unsuccessful self-management of a chronic disease such as diabetes. In an exploratory study, Gillibrand and Flynn (2001) found that patients with diabetes may externalize their control to healthcare professionals; thus, their ability to effectively cope and manage their illness greatly depends on the individual's experiences with their healthcare provider. The limitation of this study is the relatively small size (N = 18), thus generalizing the findings to a larger population may prove difficult.

Specialty populations such as medically underserved and lower socioeconomic status seem to show more vulnerability in the correlation between HLC and successful self-management of diabetes (O'Hea et al., 2009). Due to lack of resources and inaccessibility to health care, these populations are often forced to rely on their personal resources to manage their chronic illnesses. Lack of resources and inaccessibility to care often lead to erratic and inconsistent health behaviors, that in turn leads to increased morbidity and mortality (O'Hea et

al., 2009). With current economic conditions in the United States and over 44 million medically underserved individuals currently residing in the country, lack of access to care threatens to increase morbidity and mortality from chronic disease (Diabetes Data and Trends - CDC, n.d.).

One of the major challenges facing the future of healthcare in the United States is the rise of chronic conditions such as diabetes while at the same time there is an increasing shortage of medical doctors to deliver care to these individuals. By 2014, the United States will attempt to resolve the access to care dilemma by providing a national health care plan that will give all citizens access to primary care services. However, meeting this objective will be difficult without considering innovative methods for increasing the number of healthcare providers able to deliver care for chronic illness. The Centering in Care Model provides a novel approach to treating chronic disease such as diabetes while at the same time effectively using additional members of the healthcare team to deliver care.

<u>Centering in Care Model</u>

"Centering is a model of group healthcare, which incorporates three major components: *assessment*, *education*, and *support*. Group participants meet with their care provider and other group participants according to a regular schedule for a much longer period of time (usually 90-120 minutes) than a usual check-up visit," (Centering Healthcare Institute, n.d.). This model has been used to deliver healthcare in a variety of settings including prenatal care, parenting/well-child classes, smoking cessation classes, and diabetes care (Centering Healthcare Institute, n.d.). The idea of centering involves bringing together a homogeneous group of people to collectively receive health education and care. Homogeneity is defined as a group of people with shared health conditions and at similar stages of illness with regard to onset of condition and time of diagnosis (Centering Healthcare Institute, n.d.).

There are 13 essential elements which comprise the Centering in Care Model. These elements are health assessment occurs within the group space; participants are involved in self-care activities; a facilitative leadership style is used; the group is conducted in a circle; each session has an overall plan; attention is given to the core content; there is stability of group leadership; group conduct honors the contribution of each member; the composition of the group is stable, not rigid; group size is optimal to promote the process; involvement of support people is optional; opportunity for socializing with the group is provided; and there is ongoing evaluation of outcomes (Centering Healthcare Institute, n.d.). The advantages of using a Centering in Care Model are increased patient and provider satisfaction that results in improved patient outcomes (Centering Healthcare Institute, n.d.). Health care is taken out of the traditional exam room environment, and barriers between providers and patients are eliminated.

The Centering in Care Model allows for more open communication and sharing of beliefs (Massey, Rising, & Ickovics, 2006). For example, if one wished to deliver health education and care to a group of newly diagnosed individuals with diabetes this model would be used to establish a framework to deliver healthcare. In this design, groups would be created by identifying 6-10 individuals who collectively were diagnosed with diabetes within the same time frame and are experiencing the same stage of disease as evidenced by lab work, treatment regimen, and self-care. Individuals would meet as a group at regular intervals. Each of these meetings would be conducted in the same manner. Individuals begin with a routine patient intake exam. They then participate in a group education discussion on a diabetes-related topic, i.e. routine blood sugar monitoring at home. The group education session is facilitated by a healthcare professional, and active discussion amongst group members is encouraged. Individuals are seated in a circular formation for group education to facilitate discussion and

support amongst group members (Centering Healthcare Institute, n.d.). Group education and

discussion last approximately 45 minutes and are then followed by one-on-one meetings between

the healthcare provider and each individual member of the group. These individual meetings last

approximately 10 minutes and are designed to address the unique needs of each individual

member.

The Centering in Care Model promotes self-esteem and social support by delivering

health education and treatment consistently over a period of time to a single group of individuals.

Groups are homogenous and individuals increase their ability to self-manage chronic illness by

group identification and assimilation (Centering Healthcare Institute, n.d.; Ickovics et al., 2007;

Rising, 1998). Group assimilation occurs through repetition of meetings and fosters social

support among group members (Centering Healthcare Institute, n.d.). As evidenced by the

literature, social support increases an individual's ability to self-manage diabetes (Clancy et al.,

2007; Klomegah, 2006; Schillinger, Handley, Wang, & Hammer, 2009).

Historically, much of the research in the Centering in Care Model has focused on group

prenatal care, as this was the birthplace of the Centering in Healthcare Model. The use of

centering in prenatal care resulted in fewer low-birth weight and pre-term deliveries (Ickovics et

al., 2007). Centering in care for prenatal visits resulted in decreased emergency room visits

(Rising, 1998). Massey, Rising, and Ickovics (2006) showed the Centering in Care Model

helped to nurture self-growth in patients and families while helping to form a social network for

pregnant women.

In conjunction with providing significant benefits to pregnant women and their families,

Centering in Care models also help increase effectiveness and efficiency in care organizations.

According to Massey et al. (2006), group visits use conference rooms for care and education,

thus freeing up additional exam rooms for other patients for whom a group care setting would not be beneficial, such as high risk pregnancies. Rising (1998) showed that women in group prenatal care receive extensive education that results in fewer office phone calls and greater confidence in labor and newborn care.

Centering in Care is not limited to prenatal care. Many studies have described the use of the Centering in Health Care Model to deliver primary care services. In a study by Osborn and Woolley (1981), use of groups in delivering well-child care found that group visits were as efficient as individual well-child visits; however, mothers were more compliant in attending group well-child care visits as opposed to traditional visits. These findings led the researchers to suggest that social support and group dynamics encouraged higher accountability in group care participants. This, in turn, led to higher compliance in group care mothers in both attendance of visits and in self-care of their children at home (Osborn & Woolley, 1981) A controlled study was conducted to examine the use of groups for well child care in the office setting. Group visits were compared to traditional visits by assessing the efficiency, efficacy, content, and process of visits as well as patient satisfaction. The group method was efficient and required no more provider time per pair than individual visits. The group method effectively changed the process and content of the well child visits and was acceptable to the sample population. Few changes in health care utilization were found, but mothers in the experimental group completed more well child visits and sought less advice between visits than mothers in the control group. The group method offers an alternative method of care that is worthy of further investigation and implementation (Osborn & Woolley, 1981).

The Centering in Care Model has been extended to management of chronic health conditions (Centering Healthcare Institute, n.d.; Clancy, Dismuke, Magruder, Simpson, &

Bradford, 2008). Traditional research in this area has focused on care and education focused on

the patient (Centering Healthcare Institute, n.d.; Reid, 2007; Schindler Rising, Kennedy, &

Klima, 2004). The use of this model for chronic illness management results in patients acquiring

skills necessary to more effectively self-manage their diseases in their home environments

(Centering Healthcare Institute, n.d.; Clancy et al., 2008). As noted above additional benefits of

the Centering in Care Model include establishment of a social support system for patients by

providing them with a consistent homogeneous group with which to assimilate and share lived

experiences (Massey et al., 2006). From a healthcare practice perspective, using the Centering in

Care Model for diabetes ensures continuity and comprehensiveness in treatment and care, as

groups are routinely tested according to American Diabetes Association (ADA) 2010 guidelines,

and patients receive education in a consistent manner by a qualified healthcare provider

(Diabetes Statistics - American Diabetes Association, n.d.).

      Much of the research on the use of the centering model with diabetes has focused on

improvement of individual outcomes (Clancy et al., 2007; Fokkens et al., 2011; Pick, 2009;

Rosal et al., 2011; Schillinger et al., 2009). Clancy et al. (2007) reported that the Centering in

Healthcare Model may prove beneficial in helping individuals with diabetes effectively self-

manage their disease. In their study of 186 individuals with type II diabetes they evaluated the

effectiveness of group care visits. Long-term findings were promising; at 12 months patients

receiving care in group visits exhibited greater concordance with ADA process-of-care indicators

and higher screening rates for cancers of the breast and cervix over patients in traditional one-to-

one care. Davis et al. (2008) conducted a literature review to assess the effectiveness of group-

managed visits on patients with diabetes mellitus. They revealed that group care provided for

more patient engagement in care which resulted in improved patient and provider satisfaction with care.

Schillinger et al. (2009) in their study of social support and self-management of adults with diabetes (N=339), showed evidence that group managed visits increased patient self-management and increase patient perception of diabetes. While no significant hemoglobin A1C level change was noted, group visits, which included a follow-up telephone call by a nurse improved self- management of patients with fewer sick days and interruptions of activities of daily living (Schillinger et al., 2009).

Pick (2009) studied patients with diabetes (N = 234) who participated in patient participation groups (PPGs) for healthcare. It was revealed that PPGs provided patients with more information, skills and knowledge to better manage their diabetes. Forty-five percent of participants stated that PPGs helped them to better manage their medications, 57% stated that PPGs helped them better manage their diet, and 65% stated that PPGs helped them to eat healthier (Pick, 2009).

Rosal et al. (2011) used the Centering in Care Model to test whether a culturally targeted self-management intervention improved diabetes metabolic control in low-income Latinos with diabetes mellitus (N = 252). The findings were significant. The intervention resulted in significant change differences in diabetes knowledge at 12 months, self-efficacy, blood glucose self-monitoring, and diet, including dietary quality, and consumption of calories and saturated fat (Rosal et al., 2011).

Additionally, using a quasi-experimental study researchers revealed that structured group diabetes care led to improved metabolic control of diabetes (Fokkens et al., 2011). Structured care led to improvement in HbA1c and long-term improvements in blood pressure and

cholesterol compared with care-as-usual. After 1 year, the percentage of patients who did not deteriorate was higher in the structured care group, again for HbA1c, diastolic blood pressure, low-density lipoprotein cholesterol and body mass index (Fokkens et al., 2011). Review of these studies revealed that group care models can improve individual health outcomes in patients with diabetes.

One of the many benefits of a centering in care approach is the increase in access to care (Centering Healthcare Institute, n.d.). Much of the literature on group care illustrates the benefit of involving additional members of the healthcare team to provide group care. By expanding delivery of care beyond the exclusivity of a physician, the centering in group care model increases access to routine healthcare, thus increasing the ability of specialty populations like medically underserved to access ongoing healthcare they need to successfully manage their diabetes (Centering Healthcare Institute, n.d.; Jeanfreau, 2008; Partiprajak et al., 2011; Watts et al., 2009).

Researchers indicate that the Centering in Care Model can be easily implemented by additional members of the healthcare team including nurse practitioners (Jeanfreau, 2008; Watts et al., 2009). Results from a recent study by Watts et al. (2009) found that nurse practitioners (NPs) are qualified and able to deliver care to individuals with chronic illnesses via the centering in healthcare approach. The effectiveness of NPs in delivering group care to three distinct groups of chronic illness; diabetes, heart failure, and hypertension was examined. NPs were evaluated on their ability to address the six components of the Chronic Care Model: self-management support, clinical information systems, delivery system redesign, decision support, health care organization, and community resources. Although NPs group care activities entailed

all components of the Chronic Care Model, NPs were most influential in self-management support and delivery system design (Watts et al., 2009).

Jeanfreau (2008) evaluated the effect of group care visits by an advanced nurse practitioner on medically underserved patients with diabetes. Two hundred individuals with type II diabetes mellitus participated in this study. While the study terminated early due to the evacuation of hurricane Katrina, findings were promising. Individuals who participated in group care visits more effectively managed their diabetes as was evidenced by decreased systolic and diastolic blood pressures and reduced HbA1c values (Jeanfreau, 2008).

Partiprajak et al. (2011) compared ability to self-manage care in 100 patients with diabetes who were randomly assigned to either of two treatment groups: patients who received care via an advance nurse practitioner led support group, or a traditional treatment group. Researchers revealed that patients in the advanced practice nurse-led support group had lower systolic blood pressure, higher self-care abilities higher quality of life, and greater satisfaction with care, than those in the comparison group (Partiprajak et al., 2011).

In reviewing the role of the Centering in Care Model and HLC, group care models increase self-efficacy and self-management in individuals. Increased self-efficacy and self-management of diabetes, in turn, increases individual belief in his/her control over the progression of disease, aka internal health locus of control (Fokkens et al., 2011; Partiprajak et al., 2011; Watts et al., 2009), an individual's belief about his/her ability to control disease significantly impacts his/her ability to stay healthy in the face of chronic disease like diabetes.

Future Research with Locus of Control and Centering In Care Model in Diabetes

Diabetes is currently the seventh leading cause of death in the United States (Diabetes Data and Trends - CDC, n.d.). With current national initiatives to improve access to care to all citizens of the United States, the Centering in Care Model is a unique approach to caring for medically underserved individuals with diabetes. The benefits of using this model include increased patient compliance, increased patient self-efficacy, increased internal locus of control, improved health behavior, improved patient-provider relationship, and improved self-care behavior (Centering Healthcare Institute, n.d.; Clancy et al., 2007; Jeanfreau, 2008). These benefits, in turn, result in improved management of diabetes which reduces morbidity and mortality from disease (Clancy et al., 2007; Jeanfreau, 2008). Thus, use of the Centering in Care Model may be key to reducing complications from diabetes and improving the ability to live healthy with diabetes.

Although the Centering in Care Model appears to be a reliable approach to improving health locus of control and self-management behaviors for individuals diagnosed with diabetes, much of the research on this model's use in chronic disease has focused on treatment of the individual (Rising, 1998). At the present time, virtually no studies could be found by this author that implemented the Centering in Care Model to the care of families or Adults.

As suggested in literature, the family is the primary socialization unit for an individual, and as suggested by Rotter's Social Learning Theory (1954), families serve as the primary socialization environment in which individuals develop health behaviors. In addition the importance of the influence of powerful others is evident throughout the literature on health locus of control (Grotz et al., 2011; Knappe & Pinquart, 2009; Schlenk & Hart, 1984). Powerful others are often most influential on behavior adaptation or change in the face of chronic disease

(Gillibrand & Flynn, 2001; Grotz et al., 2011; Konen, Summerson, & Dignan, 1993; Tillotson & Smith, 1996). Due to the influence of powerful others and the scarcity of literature on using the Centering in Care Model for families, additional research is needed on the impact of this model in delivering healthcare to individuals in conjunction with their significant others. In an effort to improve self-care behaviors one area for future research of the effects of using the Centering in Care Model is in delivering care to adults living with diabetes.

Future research which implements group care models for families and significant others may have increased impact on diabetes management by influencing both internal and external health locus of control. By expanding this model to include the family of the individual diagnosed with diabetes there is potential to influence "powerful others." Influencing family in turn may have a bigger impact on self-management diabetes that will lead to decreased morbidity and mortality.

Belief in a person's ability to self-manage their diabetes is directly related to their partner's beliefs about their disease (Beverly & Wray, 2008). According to Beverly and Wray (2008), "People with diabetes would benefit from a supportive marriage that does not generate conflict with the behavior recommendations for diabetes management," (p. 31). The best way to promote cohesiveness in Adults' beliefs about diabetes management is to deliver care and education to them collectively as a unit (Beverly & Wray, 2008). To deliver care to adults living at the same residence, healthcare providers must initiate education and treatment that not only acknowledges the unique needs of the person suffering with diabetes, but also must address the needs of the partner. Partner needs include a sense of partner's vulnerability; partner burden; partner coping ability; and their ability to resolve conflicts (Beverly & Wray, 2008).

Schokker et al. (2010) queried 205 Adults about support satisfaction in their partners. Adults coping with a chronic illness such as diabetes typically display two main types of support behavior, active engagement and protective buffering. Active engagement is characterized by the partner being actively involved in conversations about diabetes, asking how the other partner feels, and participation in problem solving. Protective buffering, on the other hand, is characterized by denial of partner fears and pretending that everything is okay. Active engagement in Adults dealing with diabetes results in greater relationship satisfaction and ability to self-manage disease. Protective buffering results in less satisfaction in relationships and impedes a couple's ability to self-manage diabetes effectively, and high levels of active engagement may actually decrease the potential for the development of protective buffering behaviors (Schokker et al., 2010). Based on their findings, care and education that address positive strategies for Adults coping with diabetes may prove beneficial in improving relationship satisfaction for both partners, which in turn may result in improved ability to self-care for individuals with diabetes.

A recent pilot study that targeted Adults (N = 44 Adults) intervention for type II diabetes, showed that education and treatment for Adults resulted in better glycemic control (Trief et al., 2011). In this study, Trief et al. (2011) divided 44 individuals into three different types of diabetes treatments: individual intervention, Adults intervention, and individual education only. Refinement of this pilot study resulted in a current longitudinal study in long-term implications of Adults intervention for the treatment of type II diabetes. However, none of the interventions incorporate the group settings to deliver care.

Summary

Diabetes is a chronic illness which is quickly reaching epidemic proportions in the US. Of the two major classifications of diabetes, type II diabetes afflicts 90-95% of individuals diagnosed (Diagnosis and Classification of Diabetes Mellitus, n.d.). Interestingly, with lifestyle changes and dietary management, individuals with type II diabetes can effectively manage and reduce their chance of developing complications or dying from this illness (Diabetes Data and Trends - CDC, n.d.). Specialty populations such as the medically underserved are at particularly high risk of increased morbidity from diabetes (Alverson & Kessler, 2012; Philis-Tsimikas & Walker, 2001). Lack of resources and decreased access to adequate healthcare make medically underserved individuals vulnerable to increased complications from diabetes (Alverson & Kessler, 2012; Clancy et al., 2007; Jeanfreau, 2008). Much of the literature on type II diabetes shows that with ongoing primary healthcare and education that improves health locus of control can positively impact a person's ability to effectively self-manage diabetes (Grotz et al., 2011; Knappe & Pinquart, 2009; Kostka & Jachimowicz, 2010).

In addition researchers indicate that powerful others have a strong influence on a person's belief about diabetes and how they self-manage their disease (Schokker et al., 2010). Thus, implementing care and education that incorporates families and significant others can increase a person's external health locus of control. This, in turn, can impact their ability to live healthy with diabetes (Knappe & Pinquart, 2009).

The Centering in Care Model is a unique approach to delivering healthcare and education to individuals in a setting that promotes self-efficacy and social support (Centering Healthcare Institute, n.d.). Research on the use of this model in treating chronic illness is promising (Clancy et al., 2007; Davis et al., 2008; Jeanfreau, 2008; Massey et al., 2006). The benefits of using a

Centering in Care approach include increased provider and patient satisfaction, and these in turn result in improved patient outcomes (Centering Healthcare Institute, n.d.). This model also provides a cost effective means for delivering group care to medically underserved individuals while fostering an environment of social support (Centering Healthcare Institute, n.d.).

Although much of the research on use of the Centering in Care Model has focused on individual care and education, the potential use of this model to promote familial care and education is encouraging. Currently, there are no studies which investigate the use of this model to deliver care to individuals and their significant others. Future research in this area is needed as we continue to search for innovative and effective methods for improving education and care in the face of diabetes.

<div align="center">Purpose of the Study</div>

The purpose of this study was two-fold: (1) to illuminate the lived experiences of medically underserved co-residing adults (MUCA) and the barriers which complicate the management of diabetes, and (2) to examine the impact of the Centering in Care model on self-management of diabetes in MUCAs. Specifically my research questions addressed the following:

(1) What is the day-today lived experience of medically underserved adults living with type II diabetes mellitus?

(2) How does participation in group care health visits affect health locus of control in medically underserved co-residing adults living with type II diabetes mellitus?

(3) What are the effects on self-management of diabetes in medically underserved co-residing adults who participate in a group care model for health visits and education?

(4) How does having a partner participate in group care impact co-residing adults' ability to self-manage diabetes outside the care environment?

(5) What is the relation between health locus of control and physical weight, body mass index, waist circumference, and Hemoglobin A1c?

CHAPTER 3

METHODOLOGY

In this chapter I describe the methodology of this study emphasizing sampling procedure, data collection, and data analysis. It should be noted that the methodology was meticulously designed prior to the implementation of the study to ensure a comprehensive picture of diabetes management in medically underserved families in the north Georgia region. In addition both qualitative and quantitative data were collected to triangulate and fortify study findings. According to Hesse-Biber (2010), "methods triangulation refers to the use of more than one method while studying the same research question in order to examine the same dimension of a research problem" (p. 3). The goal of triangulation is convergence of data to enhance the credibility of study findings (Hesse-Biber, 2010).

<u>Research Design and Analysis</u>

A phenomenological approach was used to guide this study. In a foundational book on phenomenological research, Manen (1990) states "from a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings" (p. 5). Phenomenology, hermeneutics, and semiotics are the tenets to which this study is oriented. According to Manen (1990), phenomenology describes how a person orients to lived experiences. Hermeneutics deals with how a person interprets the "texts" of life, and semiotics refers to the linguistic approach to phenomenology (Manen, 1990).

In order to gain a comprehensive picture of the lived experience of medically underserved co-residing adults (MUCA) dealing with diabetes and the impact of a group care model on MUCA pairs, a mixed methods approach was used to collect both qualitative and

quantitative data. A concurrent triangulation strategy was used, and both qualitative and quantitative data were collected simultaneously throughout the study. According to Creswell (2009) in a concurrent triangulation approach, " the researcher collects both quantitative and qualitative data concurrently and then compares the two databases to determine if there is convergence, differences, or some combination" (p. 213). The goal of this approach is to offset weaknesses of one method with the strengths of the other method which, in turn, reinforces the interpretation of data (Creswell, 2009).

Initially qualitative data were analyzed for emergent and evolutionary themes, and then descriptive statistics on quantitative data were analyzed to determine if the quantitative findings supported the qualitative findings. This method of weighting the data was used to investigate whether the quantitative data supported the emergent and transformational themes identified in the qualitative data (Creswell, 2009). Because the quantitative data were used to support identified qualitative themes, mixing of the data did not occur until after qualitative analysis when the quantitative data was embedded to support qualitative findings (Creswell, 2009). This resulted in convergence of the data with an overall goal of increasing validity of the study via a mixed-methods design (Hesse-Biber, 2010).

Data were analyzed using a case study approach. "Case study is a strategy of inquiry in which the researcher explores in-depth a program, event, activity, process, or one or more individuals" (Creswell, 2009, p. 13). The goal of case study analysis is understanding (Stake, 2006). The group as a whole was researched as a case study, as the sample size was small (N= 10 or 5 MUCAs). This method of analyzing data acknowledged the larger group case as the integration of each of the individual pairs. According to Stake (2006) "the interactions within an entity and across entities help us recognize the case as an integrated system" (p. 3). This method

provided a more comprehensive interpretation of data which, in turn, led to a more complete understanding of diabetes management and the impact of group care on self-management in MUCAs.

<div align="center">Research Context</div>

The study was conducted in the rural community of north Georgia. Fifteen percent of north Georgia's population lives below the national poverty level and three-fifths of north Georgia's counties are designated as either medically underserved areas or medically underserved populations (Find Shortage Areas: MUA/P by State and County, 2013). According to the CDC (n.d.), the major chronic illnesses affecting north Georgia are diabetes, hypertension, and obesity. For the purpose of confidentiality, each study participant was given a numerical code which was used to identify data presented in this dissertation.

<div align="center">Research Participants</div>

Adults, ages 18-70, were recruited to participate in this research study through purposive selection from a convenient sample. According to Maxwell (2012) purposive selection is used when deliberate selection is preferred in order to provide information that can't be acquired through other choices. There are four goals for purposive selection: (1) achieving representativeness of typicality of settings, individuals, or activities; (2) adequately capture heterogeneity in the studied population; (3) deliberately examine cases that are critical for theories of study; and (4) establish particular comparisons to illuminate the reasons for differences between settings or individuals (Maxwell, 2012).   Purposive selection was used in this study because it permitted better acquisition of data that is specific to medically underserved co-residing adults (MUCA) living with diabetes.

In order to be considered for participation in this study, the MUCAs must have had at least one member who was diagnosed with adult onset diabetes as prescribed by the American Diabetes Association (Diabetes Statistics - American Diabetes Association, n.d.):

a.   A fasting plasma glucose (FPG) $\geq$ 126

b.   A Hemoglobin A1C (HgbA1C) $\geq$ 6.5%

c.   An oral glucose tolerance test (OGTT) $\geq$ 200

Due to the medically underserved's lack of ongoing access to health services and for the purposes of this study, the length of time since diagnosis was not an inclusion or exclusion criteria. Adults were considered despite their length of time since diagnosis. However, exclusion criteria included any participant who participated in group diabetes education within the last five years, as this may have potentially affected the adult's interest in completing all group care visits.

Recruitment of participants was done at the Appalachian Nurse Practitioner Clinic (ANPC). This site was chosen for recruitment for several reasons: (1) the ANPC is a federally funded clinic that provides primary care services to medically uninsured and underserved residents of north Georgia; (2) approximately 85% of the patients that receive care at the ANPC have a diagnosis of diabetes; (3) the ANPC advisory board and project director were very interested in supporting the research; and (4) I believed there would be increased interest and participation in research by patients due to their familiarity with researcher as a care provider in the clinic. Recruitment flyers were placed at the check-in desk and in each of the examination rooms of the clinic (see Appendix B). Potential adult participants were also identified by health care providers at the ANPC and given a recruitment letter (See Appendix C).

For the purposes of this study adult partners were defined as two people living at the same residence. This included married partners, same sex partners, co-residing partners, and dyads such as parent-child and sibling-sibling. An adult was defined as either male or female age 18-70, as consistent with the American Diabetes Association guidelines for recommendations for adults with diabetes (Diabetes Statistics - American Diabetes Association, n.d.). Due to the specialized recommendations for the management of pregnant women with diabetes, no pregnant women were included in the study.

Following oral explanation of study purpose and procedures, the potential adult participants were asked if they are interested in participating in the study. If they were interested, signed informed consent was obtained from all participants (Appendix D). Study participants were notified that they may change their minds about participating at any time during the study without penalty. In addition to informed consent adults completed a pre-participation screening via telephone to determine eligibility for participation in research study (Appendix E).

Each participant was required to have a cell phone with texting and/or messaging capabilities. Study participants were also required to possess basic cell phone skills. Basic skills included but were not limited to texting, turning on/off phone, listening to messages, and receiving both verbal and/or text messages. The pre-participation questionnaire was used to determine if a participant had a cell phone and basic cell phone skills listed above. In addition the pre-participation questionnaire assessed the potential of pregnancy and the ability of participants with diabetes to check their blood sugars with a blood glucose monitor.

Diagnosis of type II diabetes was initially confirmed by laboratory documentation from the participant's health record and later confirmed with a preliminary HgbA1c conducted at the

first group meeting. Hemoglobin A1c (HgbA1c) is a diagnostic blood test that can be used to evaluate the average daily blood glucose of an individual for the previous 90-day interval prior to lab draw (Diabetes Statistics - American Diabetes Association, n.d.). According to Gillett (2009), "The relationship between A1c and average glucose levels is not perfect" (p.1327). Despite the evidence which suggests an abnormal hemoglobin value can create a false HgbA1c level, researchers indicate that a HgbA1c in addition to laboratory data such as abnormal fasting plasma glucose or an elevated oral glucose tolerance test (OGTT), adequately supports a diagnosis of diabetes (Gillett, 2009). In accordance with American Diabetes Association guidelines, study participants received a diagnosis of diabetes if they presented with a prior history of abnormal lab values and/or diagnosis of diabetes, and diagnosis was confirmed if their HgbA1c at the first group meeting was above 6.5% (Diabetes Statistics - American Diabetes Association, n.d.; Gillett, 2009).

All lab studies, research materials, and tools were provided to participants free of charge. In addition to free laboratory studies and research materials, participants received the following incentives to encourage attendance of all group care visits and completion of all components of the research study: (1) All medically underserved co-residing adults (MUCA) who completed the research study received a $25 gift card to Walmart; and (2) each participant diagnosed with diabetes received a glucose monitor and a six-month supply of testing strips. Not only were these incentives designed to keep adults participating in study activities, but they also served to encourage adults to continue to self-manage diabetes following completion of the study. Incentives were consistent with the routine cost of receiving care if participants were not enrolled in the study. These costs were estimated as follows: (1) Accucheck Aviva Diabetic Monitor = $17.00; (2) Six month supply of Accucheck Aviva Test Strips = $50.00; (3) Cost of Laboratory

Tests in Clinic: HgbA1C = $66.00; Random Blood Glucose Screen = $5.00. These costs were calculated based on current charges by the ANPC.

A total of 36 participants (18 MUCAs) was targeted for participation. According to Terrell (2012), a minimum of 30 participants is required to be able to conduct statistical analyses on dependent variables. By targeting 36 total participants (18 MUCAs), this allowed for a minimal sample size for quantitative analysis using descriptive statistics in the event that a MUCA decides to drop out of the study. This target also allowed for three groups of 12 individuals (6 MUCAs per group). According to Sharon Rising, CEO of the Centering in Healthcare Institute, ideal composition of each group was 12 members or 6 MUCAs. Minimum recommendation for size of group is 6 members or 3 MUCAs (S. Rising, personal communication, January 25, 2013).

I spent an initial two months recruiting for the first group and following the attempted recruitment of 74 individuals (37 MUCA pairs), 10 individuals (5 MUCA pairs) agreed to participate. Following the first group recruitment, an additional two months of recruitment was attempted with an additional 90 individuals (45 MUCA pairs); however, none of them agreed to participate. Although difficulty in recruitment was anticipated, use of a convenience sample from a clinic at which I practiced was thought to have yielded a larger number of participants. A poll of individuals refusing to participate revealed the most common reason for decline was a general distrust of research.

After the initial recruitment with a flyer, letter, or recommendation by another provider, 160 potential participants called the research phone and/or came by the clinic to discuss the study with me. For each of these individuals I participated in a 15-20 minute explanation of the study and study requirements. Following the explanation of the study, many of the adults I spoke with

expressed interest in the study. The following are samples of comments made by these individuals:

"This sounds like an interesting way to meet with a provider."

"I like the idea of the new meter and I definitely could use some new information about diabetes."

"I like the idea of meeting other people who have diabetes like me."

Several of the individuals I spoke with initially asked if they could talk it over with their adult partner and call me back with an answer. I responded by thanking them for consideration and verifying the time they anticipated calling me back. I also asked their permission to call them back if I had not heard from them by the agreed call back time. Fifty-five of the potential participants called me back and declined to participate, and I returned phone calls to 105 individuals, who also declined. I asked these individuals why they refused to participate and, the following statements are samples of comments I received about why adults were hesitant to participate:

"I am scared of research."

"I have heard about how research takes advantage of people."

"My (adult partner) is afraid of participating in research."

"I am nervous about giving personal information about myself to you. I am worried about what will happen to it"

"I am worried that I won't get my disability if they find out I participated in your research."

"I am nervous about who you will discuss my private business with."

"I don't want my struggles with diabetes shared with other people. It might come back to haunt me."

Despite my efforts at further communication with these individuals to reassure them about participating in the study, none of them agreed to participate. Interestingly, literature indicates that one of the main issues in delivering care to medically underserved populations is fear of exploitation (Duffy, 2008). According to Duffy (2008), "there is some concern about feeling vulnerable on another level and sharing deep and personal feelings and then not having them treasured, valued, or reciprocated" (p. 69). Individuals who were recruited for this study expressed a fear of perceived repercussions of participating in research. For example, several adults vocalized fear over being denied disability benefits if they participated in the research study and actually showed improvement in their diabetes management. Consistent with the literature, medically underserved individuals live in a world of vulnerability in which they are forced to approach experiences with a cautionary mistrust. For this study, the small sample size is additional data which highlights the complexity of being medically underserved with a chronic disease like diabetes.

For me personally the rejection by potential participants represented the gap between my desired patient perception of me as a trusted provider and the reality of what these individuals believed about me as a healthcare provider. Although initially I was perplexed and saddened by this realization, it became the impetus to be as transparent as I could with study participants so that I could learn about their reality. In addition, it created an inherent motivation in me to protect participants from harm. Qualitative phenomenology involves textual reflection on lived experiences with the intention of increasing thoughtfulness and practical resourcefulness (Manen, 1990). I realized that living through this recruitment experience gave me deeper, more

meaningful insight into both my medically underserved patients and myself as both a healthcare provider and a researcher.

My final study yielded 10 participants (5 MUCA pairs). Nine study participants completed all phases of the study, and one study participant completed all interviews, health statistics, and questionnaires, but attended four group care meetings. This participant missed the last two group care meetings due to a new job which required him to work on the evenings of group meetings. Interestingly, this participant's partner continued to attend all group meetings and relayed all group information to the absent partner at home.

According to Manen (1990),

Lived experience is the starting point and end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once reflexive reliving and reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her own lived experience. (p. 36)

To establish an appreciation of the lived experiences of the study participants I must first introduce them to you. Next I will share the stories of each MUCA who participated in this study. As suggested by the literature on phenomenology, to truly understand the real world experience of individuals, one must understand how lived experiences have shaped a person's "truth" about a particular phenomenon (Crabtree & Miller, 1999; Creswell, 2009; Grbich, 1999; Manen, 1990). It is important to understand the life histories of study participants to be able to "reduce individual experiences with a phenomenon to a description of the universal essence," of diabetes in MUCAs (Creswell, 2009, p. 58). The following stories contain information I have gained from both my previous encounters with study participants and initial interviews I conducted as part of this study.

Participant Stories

To understand the impact of diabetes in medically underserved adults, one must first understand the history behind the development of the disease. In illuminating participant stories, I share some very personal accounts of their lives. Study participants consented to sharing the information contained in these stories, and in an effort to protect participants' privacy I have changed some of the details which could jeopardize participant confidentiality. Ages, descriptions of families, occupations, and residences have been altered to protect the identities of study participants. In changing certain details, I have insured to not change any part of the participants' stories which impact the development and lived experience of diabetes.

Participant 001A and 001B. Participant 001A and 001B are a daughter and mother, respectively, both diagnosed with adult onset diabetes. 001A was 38 years old and 001B was 59 years old at the time of this study. They live together on a family-owned property in the Appalachian foothills. Five generations of family have owned, worked, and lived on this property. In addition to the mother and daughter, currently there are two other siblings, two grandchildren, and 001A's boyfriend residing on the property. All adults in the family have completed high school, and 001B's oldest child has completed a degree at a trade school. The two grandchildren are in middle school. Participant 001B's youngest child was enrolled in college but left school due to the difficulty of course work.

The participant daughter (001A) is a middle child. She applied to college several years ago, was accepted, but did not go. She became very depressed about not being able to attend college, which resulted in a suicide attempt. She was diagnosed with diabetes shortly after this suicide attempt and was told she developed diabetes as a result of liver destruction from her attempted suicide. In addition to diabetes, she suffers from morbid obesity (current weight 396

lbs.), high blood pressure, chronic back pain, arthritis, peripheral artery disease, high cholesterol, gall bladder disease, gastroesophageal reflux, carpal tunnel syndrome, asthma, and depression. Her chronic back pain is related to degenerative disc disease resulting from her obesity and other illnesses. She walks with a cane and can only walk short distances and sit upright in a chair for about two hours at a time. She has received treatment at a pain clinic, and currently she takes five different prescription pain medications. In addition to her pain medications, she takes nine other medications each day, for a total of fourteen prescription medications daily. She has not worked in the last ten years and receives all of her support from her mother. Her boyfriend of five years lives with her, does not work, and is also supported by her mother. When she needs extra money for healthcare, she borrows it from her older sibling, the only working family member.

In early 2012, 001A's father unexpectedly died from a diabetes-related complication. Her father's untimely death has devastated 001A, and over the past year, she has struggled to get her diabetes under control. The following excerpt from my first interview with 001A and 001B illustrates the impact of 001A's father's death on her:

> *I watched my daddy die from it. I watched my daddy die a senseless death just because he was fat and he was diabetic and they gave him the wrong medicine. And he swelled up from the medicine because it was a reaction from the medicine and I never ... can't say never... There's only two people in this world that I would like to blow their brains out and I wouldn't feel bad about it. It is the doctor that sent my daddy home and told him he was dying when there wasn't anything wrong with him. They took more fluid off of him in (X hospital) ER than they did up here. They didn't try to help Daddy. And it just makes me really mad because it was a senseless death. And I need my daddy. I've always*

needed my daddy. And I know it is sad for me to say that we might started taking care of

Daddy at an early age but he was there for everything. All the bad, all the good through

everything he was there.

Participant 001B (mother) was diagnosed with diabetes around the same time as her

daughter. At that time her husband was alive, and she was able to work outside the home. She

had medical coverage, and one day she got very sick at work, was sent to her doctor, and

diagnosed with diabetes. Although she was shocked by this diagnosis, she was very familiar

with diabetes. She had numerous family members with diabetes including her mother, father,

husband, sisters, and several aunts. She stopped working outside the home in 2007, when her

husband became house-bound due to complications from diabetes. As a result she lost her

insurance and was referred to the medically underserved clinic for her healthcare. In addition to

diabetes, participant 001B suffers with high blood pressure, high cholesterol, obesity,

depression, gall bladder disease, and gastroesophageal reflux disease. She developed depression

following the unexpected death of her husband. In Spring 2013, she was admitted to the

emergency room for uncontrollable nausea, vomiting and diarrhea for over 48 hours and

diagnosed with an acute gall bladder attack. She was advised at that time to have her gall

bladder removed, but because she had no medical insurance and the condition was not life

threatening, the hospital discharged her home. After six months of negotiation with hospital, the

medically underserved clinic was able to refer for gall bladder removal. Her recovery from that

surgery was complicated due to her body size and her uncontrolled diabetes. As a result she

returned to the emergency room one week following her surgery for a paralyzed colon.

She was told upon arrival at the emergency room that if her condition had not been life

threatening she would have had to pay $500 before the physician would see her. Since her

condition was life threatening she was admitted to the emergency room for 24 hours and had a successful reversal of her paralyzed colon.

Participants 001A and 001B and their family live off the modest income of the eldest sibling and the father's death benefits. Every month they make choices between food for the family and putting gas in the one shared car that they own. Between the two participants they take 26 different medications multiple times a day each month – about 80% of these medications are provided free to them through a drug assistance program at the clinic. They often go without necessary supplies to keep their diabetes controlled, such as blood glucose monitors and testing strips. In addition to healthcare at the clinic, both mother and daughter receive discounted mental health care at an outpatient facility. Both mother and daughter have been patients at the medically underserved clinic since it opened.

Participant 002A and 002B. Participant 002A and 002B are daughter and mother, respectively. Participant 002A was diagnosed with diabetes about five years ago after suddenly losing her vision one day. The following excerpt from my first interview with 002A and 002B describes how 002A was diagnosed with diabetes:

> *Mine was..uh.. actually a shock. Before I was diagnosed I had lost eyesight in my right eye. The blood and fluid pushed up against my retina and damaged my retina. Um.. approximately about 8 months later I was diagnosed as being diabetic and um.. that's how I became ..I found out. I didn't know anything about it*

She is 35 years old and in addition to diabetes has high blood pressure, high cholesterol, peripheral vascular disease, morbid obesity, asthma, and gastric reflux disease. She also takes medication for episodes of depression related to her diabetes and obesity. She works at a

construction plant but is unable to afford the employee contribution to get health insurance. She has been a patient at the medically underserved clinic for two years.

She takes 12 different medications per day including two different types of insulin. This requires her to take five injections of insulin each day in addition to sticking her finger for blood six times daily. She often misses her insulin doses and blood sugar checks when she is at work because she is not permitted to take more than her one allotted break for lunch.

Participant 002B, 65 years old, was diagnosed with diabetes approximately three years ago at a routine health exam at her doctor's office. She was able to have an annual health visit with her doctor under the basic Medicare coverage she receives via her husband's benefits. However, she is not able to see her physician as frequently as he has requested for her diabetes due to her family's finances and Medicare's lack of reimbursement for those visits. She takes oral medicine for her diabetes twice daily and has been fairly well-controlled on her medication. In addition to diabetes, she takes a medication for high cholesterol. She works outside the home as a housekeeper, part-time. She has a long family history of diabetes which includes her mother and father, two uncles, and one sister. All of her immediate family members have died from a diabetes-related complication. She currently lives with her husband and three adult children. Her husband also has diabetes and is currently on insulin to control his diabetes.

Participant 003A and 003B.   Participants 003A and 003B are daughter-in-law and mother-in-law, respectively. They live together in a home with both of their husbands and participant 003A's five year old son. Participant 003A, 25 years of age, was first diagnosed with gestational diabetes when she was pregnant with her daughter. She later went on to develop adult onset diabetes two years following the birth of her son. She has been unemployed since 2011 and that has left her unable to afford her diabetic medical supplies. As a result her diabetes

has been uncontrolled since then. She graduated from school as a patient care technician in Spring 2011 but has been unable to find a job. She has been a patient of mine at the medically underserved clinic since then. She currently is on insulin twice daily for diabetes and two oral medications for high blood pressure and high cholesterol. She frequently runs out of her medications due to her inability to afford to come in for appointments or pay $4 for her medications from the Walmart pharmacy.

Participant 003B, 58 years old, does not have diabetes, but has an exhaustive list of family members with diabetes which includes both parents and eleven brothers and sisters. She is in relatively good health, but admits she has not seen a healthcare provider in over seven years – this was the last time she had health benefits to afford to see a provider. She is a homemaker and prides herself on caring for her family, including her son, daughter-in-law and grandson who reside in the home with her and her husband. Participant 003B attended school until the 6th grade, and she frequently tries to hide her limited ability to read. Often she relies on her daughter-in-law to explain things she doesn't understand. She is concerned about her risk of diabetes due to what she has experienced with her family, but doesn't completely understand the disease itself. Most of what she knows about diabetes she has learned from 003A, her daughter-in-law. Her daughter-in-law is the only relative with diabetes that she has not seen suffer blindness, limb loss, or death from diabetes. 003B's mother died in her home from diabetes about four years ago. 003B and her sister cared for their mother up until her death. The following excerpt from my first interview with 003A and 003B details an emotional account of 003B's experience with her mother's death:

Yeah she had one problem on top of another problem. You know she was in and out of

the hospital with emphysema. And don't know if she had cancer cause she was the type

that didn't tell you everything. Her stomach swelled and everything. But she wouldn't ever tell you everything. I know the sugar took a toll on her. She would swell a lot. Yeah her feet and legs would just bust, you know just ooze out stuff. And my momma was the worker. Once it hit her she wasn't able to work or nothing. She worked at the nursing home for years, but it's like when it hit her it's just like her health hit her and just...(003B gets teary-eyed and stops talking)

Participant 004A and 004B. Participants 004A, 51 years, and 004B, 42 years, are wife and husband respectively. Both individuals were born and raised in South Carolina. Participant 004A has a long family history of diabetes. Her siblings, mother, and father all died from diabetes related complications. As a child she was hospitalized frequently due to a chronic respiratory illness. Participant 004A also reported a long history of domestic violence. As a young child she recalled being hit forcibly in the head by an adult relative, and this resulted in hearing loss in one ear and strabismus in one eye. She married her first husband as a teenager when she became pregnant: however, due to a domestic dispute she lost the pregnancy and divorced her husband. She met her current husband 12 years ago, and 10 years ago, they adopted two adolescent daughters. In addition to their daughters they have a five-year old grandson who also resides in their home.

Participant 004A was diagnosed with "pre-diabetes" in 2005. In 2007 she developed diabetes which she was informed was the result of chronic steroid destruction of her pancreas and liver. I first met her in 2008. At that time she had run out of her medications and was dismissed from her other provider's practice due to loss of insurance coverage. Although we initially tried to get her blood sugar controlled with oral medications, unfortunately in late 2008 she was placed on injectable insulin for diabetes control. I remember this visit clearly as her

response to going on insulin disturbed me greatly. When I explained about the need for insulin, she burst into tears and said, "No, I don't want insulin. I will die if you put me on insulin. All of my family members died once they went on insulin." It took several other appointments before I was able to convince her to begin insulin.

In addition to diabetes, participant 004A suffers with high blood pressure, high cholesterol, gastric reflux disease, peripheral vascular disease, depression, asthma, and stage one chronic kidney disease. She works as a hotel clerk, and her job often requires her to skip meals and miss her mid-day blood sugar checks and insulin. She often monitors her blood sugar by how she feels and doses her insulin based on her "guesstimate" of what she believes her blood sugar is. She is currently on 15 prescription medications, most of which she gets via the patient assistance medication program at the clinic. The remainder of the medications she gets from the local Walmart at the discounted $4 price.

Participant 004B is a part-time carpenter. When he gets work he is often on the road for several days at a time. At the time of this study, he was not a patient at the ANPC. He also had a strong family history of high blood pressure and diabetes, and complained that he had episodes of dizziness and headache off and on for the last four years. In addition he has experienced extreme fatigue for the last year. He has been a heavy cigarette smoker for the last 20 years (currently he smokes two packs of cigarettes per day). He was a little hesitant to participate in the research study initially, but was encouraged by his wife and his own concern that he may be developing diabetes and/or high blood pressure.

In July 2012, participants 004A and 004B were in a terrible car accident that resulted in a severe head injury for 004A. She spent two weeks in the hospital intensive care unit and has suffered some short-term memory loss. She has a twelve-inch scar that starts at her mid-

forehead and extends to her hind scalp from the accident and subsequent head injury repair. Her boss at the hotel was forced to reduce her hours to part-time due to her extended recovery and continued physical impairments. This has made maintenance of her health issues even more challenging with reduced finances and increasing costs of medications and supplies. The following excerpt from my first interview with 004A and 004B illustrates the difficult decisions 004A faces each day as she tries to balance her socioeconomic status and her blood glucose control:

> *Yeah, and then the finances of it are not so easy either. You know, I mean it's hard sometimes. I mean with his job, if it rains, he's not working. So then the only income you have coming in is mine. So, then do I go to the store and buy a head of lettuce, a pound of tomatoes and some cucumbers and we eat vegetables, or do I purchase steak and potatoes because I know he needs something substantial to eat to get him through the day. So that he's not out there passing out in a truck because he's not being nutritionally taken care of along with the heat. And then I think of myself and say okay if you grab some cottage cheese, some peaches, or something and throw it in here and you grab some bananas, but then you start adding all that up and it gets very very expensive. Very expensive. So sometimes the easier choices we make for our food for our home are financially based you know. Um, it's not ... you try to be health conscious about it but you find out that Country Crock has got only 1.5 grams of saturated fat in it and Smart Balance has 3.5 you go you know what I ain't giving up the crock, you know. This Smart Balance has got too much of this although it's supposed to be healthier for me. But you know Country Crock offers no trans fats, lesser amounts of carbohydrates, monosaturated fats and saturated fats....oh my God, I am telling you.*

Participant 005A and 005B. Participant 005A and 005B are husband and wife respectively. 005A is 47 years old, and 005B is 37 years old. They have been married for five years, and each of them was previously married and divorced. Participant 005A has two adult sons, who until recently were estranged from him. Participant 005B never had any children. Participant 005A was diagnosed with diabetes in 2005 and shortly thereafter lost his job and his insurance benefits resulting in lack of access to his healthcare provider. He came to the ANPC with a blood sugar of 600. A normal blood sugar on an adult is less than 140 (Diabetes Statistics - American Diabetes Association, n.d.).

Participant 005A reported that his father had diabetes. As an adult he cared for his ailing father and recounted memories of coming home from work and finding his father unconscious on the floor. He recalled not knowing what to do, and how frightened he was. His belief was if he didn't talk about his diabetes and just kept going on with life, he didn't have to die from diabetes like his father did. The following excerpt from my first interview with 005A illustrates how witnessing the effects of diabetes on his father shaped his own beliefs about his own diabetes:

> *Well, I wasn't real happy about it because I saw my father deal with it for the last couple years of his life. Taking shots two or three times a day and uh, the method he was using to calculate how much insulin he was using wasn't working cause I had to pick him up and carry him to an ambulance once. I didn't know nothing about it so I didn't know if I stuck a sack full of sugar under his tongue he probably come out of it, you know?*
> *So when we discussed it, I just didn't want to take any shots you know, cause I had seen my father go with it. I was just stubborn. I just decided if I can't level it off with pills, I just won't level it off. To hell with it.*

In 2012, participant 005A went to the emergency room with an upset stomach. Upon admission he was diagnosed with a massive heart attack and was rushed into surgery. He reported that due to diabetes destruction of his nerves he was unable to feel the usual symptoms of a heart attack – chest pain, shortness of breath, and numbness that radiates down the left arm. Following his heart attack, he was given charity care by the hospital which permitted him access to a cardiologist. In addition to his cardiac care, the cardiologist managed his diabetes in conjunction with the ANPC. At the start of this study, participant 005A was still not checking his blood sugar regularly due to the cost of supplies and his belief that he instinctively knew his blood sugar was elevated but did not feel bad. 005A reported that he is most alarmed by the ongoing nightmares he has been experiencing since his heart attack. The nightmares are very real to him. The following excerpt from my first interview with 005A and 005B details the impact of 005A's nightmares:

> One night finally after all this stuff, (005B) was in one of them. And I told her she had graduated into the clan because she was in my dreams. (005B laughs). You know I dream about people that just like you and me sitting here. I dream about people that is so real I wake up and think, what the hell was that person ....how do I know that person that they could come into my dream? I just don't know how I manufacture these people. They're just as real...
>
> **005B:** Yeah, very real. He got me thinking we had ghosts in the house. He'd see a little kid come through the bedroom... a little boy or little girl in the bedroom and he take them toys to play and then the next night he's say a lady come in and be picking up toys and stuffed animals and hover over him and smile. And they're so vivid and colorful...

In addition to diabetes, he suffers with high blood pressure, high cholesterol, cardiac disease, and anxiety. He currently works intermittently in a security position with variable hours that frequently alter his eating and sleeping schedules. This further complicates getting his diabetes under control.

Participant 005B does not have diabetes. She has a long family history of diabetes and was very familiar with diabetes treatment and medication. She wanted to participate in this study in hopes of learning some new ways to keep her husband healthy. She stated that since his heart attack her husband has not been the same, and it is beginning to take a toll on their marriage. She expressed feelings that she was forced into the role of caretaker for him and although she does not mind, she fears that if something doesn't change he will not be well enough to take care of her if she ever needs it.

Participant 005B works as a cafeteria attendant. She has access to healthcare benefits but admits that due to the high required employee contribution, she is only able to afford catastrophic coverage for her and her husband. This does not provide them any primary care services. She fears that if the charity care they receive from the cardiologist runs out, her husband will die. Because both she and her husband work, neither of them qualify for many of the medication drug programs, and she admits that many of her husband's medications are costly.

Participant 005B was also interested in information about her own health and her risk of developing diabetes. She reported that she has sisters, aunts and a mother who all had diabetes. She also stated that none of her family members adhere to the medical advice they receive about diabetes. "It is like they just believe that it is going to kill them anyway, so they are going to

enjoy their life while they are living it." She, however, was interested in preventing diabetes but didn't know any real strategies that worked given her life and socioeconomic status.

These stories represent the classic picture of the medically underserved. Voices who by most healthcare institutions have been labeled "noncompliant" due to their inability to follow established treatment plans. They are individuals who have had sporadic experiences with primary care and preventative care and base many of their judgments about diabetes on personal life experiences. They represent a population of more than 25 million in the US who struggle between not wanting to die from a disease like diabetes but cannot afford the necessary tools and education to keep them healthy. As a result they place their health in the hands of random healthcare providers when they receive access, or at worst, they leave their health to chance, gauging their disease management by how they physically feel on any given day. My goal in studying them is to gain a richer understanding of their lives as a researcher, a healthcare provider, and a human being and use an innovative new means of delivering care to foster and improve self-management of diabetes outside the healthcare setting.

<u>Instruments Used in Data Collection</u>

Multiple instruments were used in the data collection process. Below is an outline of the instruments used in this study. Copies of questionnaires, interview questions, MHLCS, and passport to wellness cards can be found as indicated below in the appendices that follow this document.

Table 3.1
Instruments Used in Research Study

Instrument	Brief Description	Group(s) that completed	Appendix
Pre-participation Screening Questionnaire	Screening instrument to assure participants qualify based on inclusion criteria	All participants individually	E
Pre- and Post-Interview Questions	Interview question guide used for all study participants	All adult participants in pairs	F
MHLCS	Multidimensional Health Locus of Control Scale was used to measure both pre-, mid-, and post- participation locus of control	All participants individually	G
Passport to Wellness Card	A postcard sized document which each study participant completed at each group care meeting. These cards served as logs for health statistical data.	All adult participants	J
Transcripts of Interviews	Both pre-participation and post-participation interviews were transcribed and member-checked with participants prior to data analysis.	All adult participants	Not included
Field notes	Field notes were documented following all group care meetings by researcher. Since none of the group care meetings were audio or video taped, field notes served to document interactions during group care classes and general thought and impressions of researcher	Researcher	Not included

Data Collection Procedures

In observance of the research design, the following instruments and procedures were used to

collect data for this study:

Pre-participation Screening Questionnaire. Initially each participant individually completed

a pre-participation screening with researcher via telephone (Appendix E). The purpose of the

initial individual screening was to verify participants' eligibility to participate in study.

Initial interview with researcher. Following pre-participation screening each medically underserved co-residing adult pair (MUCA) was interviewed face-to-face to collect baseline data on how they self-manage diabetes. Each of these interviews lasted approximately 90 minutes and was conducted prior to the MUCA participating in group care meetings. Lists of pre- and post-participation interview questions are located in Appendix F. An open-ended question design was used for both pre- and post-participation interviews. According to Grbich (1999) open-ended questions generally fall into two categories: descriptive and probing. The goal of descriptive questions is to elicit extensive answers from participants which also acknowledges their expert knowledge on the subject matter (Grbich, 1999). Since this study's focus was the lived experience of MUCAs with diabetes, descriptive questions were used to obtain study participants perspectives.

Probing open-ended questions are designed to elicit additional clarifying information from study participants (Grbich, 1999). In this study probing cues and questions were used to establish clarity in understanding participants' responses. In addition probing cues and questions gave evidence of active listening by the researcher and helped clarify and explain participant responses (Grbich, 1999).

Interviews were semi-structured with open-ended questions to permit the participants to relate their stories of diabetes in their lives. Interviews were designed to encourage participants to explain what diabetes means to them in their particular life experience. Depth interviewing is designed to generate stories through use of direct and open-ended questions (Crabtree & Miller, 1999). This method of interviewing was chosen because of my desire to gain a comprehensive view of what the impact of a diagnosis of diabetes had on a family who is medically underserved and how their belief system and life circumstances impacted their ability to follow a

recommended healthcare regimen. According to Maxwell (2012), interviewing is both an efficient and a valid method for understanding another person's perspective.

According to Maxwell (2012), research questions should frame what you want to know, thus one should not try to conceal research questions. My questions directly inquired about participants' personal experience and knowledge about diabetes and accessing healthcare. According to Maxwell (2012), a researcher should anticipate how a questions will actually work in practice, thus it was recommended that a researcher get feedback on interview questions via test piloting or receiving feedback from others. I shared my questions with fellow practitioners who work in the ANPC to get their feedback and made minor adjustments to them prior to submitting them to the University of Georgia Institutional Review Board for approval. In addition following the recruitment of participants and before the initial interviews with MUCAs, I informally test-piloted some of the pre-participation questions on other patients in the ANPC who did not participate in the study. No additional changes to interview questions were made following this test-pilot.

  Multidimensional Health Locus of Control Scale (MHLCS). Each study participant completed a written Form C of the Multidimensional Health Locus of Control Scale (MHLCS) at three points during the study: (1) initially before beginning classes; (2) midway through participation after the third group meeting; and (3) one month following the completion of the classes. I chose Form C of the MHLCS for this study because it was designed for use on individuals in regard to a specific health condition (Wallston & Wallston, 1981). Each participant had a unique identifier used in place of a name or identifying information. The MHLCS form was modified for participants diagnosed with diabetes to include the word "diabetes" in place of the word "health" (Appendix G).

Form C of the MHLCS uses three, six-item variables to evaluate the origin of health locus of control (internal or external) in an individual. The possible range of scores for each variable subscale is 6-36 points. The higher the score on a subscale, the more likely an individual's health locus of control is defined by that subscale. For example, researchers suggest that a score of 20 on the internal variable subscale suggests an individual has an internal health locus of control and believes that his/her health is a result of their own choice of behavior (Wallston, 2005). High scores on either the chance or powerful others subscales suggest that an individual has an external health locus of control, meaning that he/she believes that health is controlled by individuals or circumstances outside of their control (Wallston, 2005). As discussed in Chapter 2 of this dissertation, researchers suggest that individuals who have an internal health locus of control are better able to manage a chronic disease such as diabetes (Grotz et al., 2011; Knappe & Pinquart, 2009; Kostka & Jachimowicz, 2010; O'Hea et al., 2009). However, some researchers suggest that patients with diabetes exhibit a high external locus of control (Gillibrand & Flynn, 2001; Hummer et al., 2011; O'Hea et al., 2009).

According to literature, the MHLCS is a valid measure of health locus of control (Wallston, 2005). In the initial studies by Wallston (2005), the variables of the MHLCS were tested for internal consistency, predictive validity, and test – retest reliability and were found to be homogeneously consistent over a seven-month period of time. The powerful other variable slightly increased with age, lower social status, and acute illness. The MHLCS has been used in hundreds of studies and the reliability varies with *Cronbach alphas* in the .60–.75 range and test–retest stability coefficients ranging from .60–.70 (Wallston, 2005) .

Wallston (2005) explains that the MHLCS has three different forms (A, B, C). Form C was chosen for this study because evidence shows that Form C deals with a person's beliefs about an

illness (Wallston, 2005). Form C was developed in 1989, and in early correlational studies

between Form C and a previously evidenced Form B, Form C showed positive correlations

between internal, chance, and powerful others subscales ($r =$.59, .65, and .55 respectively)

(Wallston, 2005). This gave evidence of criterion-related validity of Form C. In another study of

chronic pain, patients exposed to a six-week pain management program, Form C showed a

significant decrease in external locus of control and an increase in internal locus of control.

Theoretically researchers predicted this exact change following exposure to a pain management

program, thus this study gave evidence of construct validity of Form C (Wallston, 2005).

Group care meetings. Following the initial interview, MUCAs participated in six weekly

group care sessions, each lasting approximately 90 minutes. Six sessions are consistent with the

guidelines of the Centering in Care Model (S. Rising, personal conversation, January 25, 2013).

Each session was guided by a diabetes self-management theme as recommended by the

American Diabetes Association (see Appendix H) and included the following components:

- o An initial 30 minute check-in in which each individual participant collected their

    own health vital statistics at health stations set up in the meeting area, and then

    met with me, one-on-one, for approximately 5 minutes to discuss their individual

    plan of care.

- o A 60-minute education session on a diabetes education topic. Education topics

    were congruent with the guidelines for diabetes education as recommended by the

    American Diabetes Association (see Appendix H). A sample group care visit

    outline is included in Appendix I.

At the beginning of each session the following health vital statistics were collected by each

study participant: height, weight, basal metabolic index (BMI), blood pressure, and pulse. Vital

statistics were collected at self-monitoring health stations which were located throughout the

meeting area, and recorded by participants on weekly Passport to Wellness Cards (Appendix J).

Height data was collected one time only at the initial session because height is not likely to

change over the course of the study. BMI was collected at each group meeting, and at the final

interview with each MUCA. BMI is a measurement to indicate the relative normalcy of weight

in a person. Researchers suggest that increased BMI is directly correlated with an increased risk

of diabetes and diabetes-related complications (Sullivan, Morrato, Ghushchyan, Wyatt, & Hill,

2005).

All data were used to evaluate the impact of group care not only on the individual diagnosed

with diabetes but also the co-residing partner of the participant diagnosed with diabetes.   In

addition waist circumference was measured at the first group care meeting and at the final

interview. According to Janssen, Katzmarzyk, and Ross (2004), waist circumference is often a

better predictor than BMI of an individual's risk for a diabetes related complication, particularly

with type II diabetes as there is a direct link between obesity and its development. As

recommended by Sharon Rising, CEO of Centering in Healthcare Institute, the researcher

facilitated participants in collecting their own vital statistics (S. Rising, personal phone

conversation, January 25, 2013).

Prior to participation in the group care meetings, a Hemoglobin A1c (HgbA1c) was drawn on

participants with type II diabetes to confirm diagnosis and obtain baseline lab work. In addition,

random blood glucoses (RBG) were drawn on all participants diagnosed with diabetes at each

group meeting. Participants not diagnosed with diabetes were offered HgbA1c and RBG

analysis if they prefer for their own knowledge purposes. HgbA1c was repeated six weeks

following completion of the study. All participants not diagnosed with diabetes elected to

participate in both HgbA1c tests, but only participated in RBG at the first group meeting. As discussed above, researchers suggest that HgbA1c is a valuable predictor of diabetes control in conjunction with other lab values such as plasma glucose (Gillett, 2009).

Each participant with a diagnosis of diabetes was given a blood glucose monitor and instructed to check their blood sugar at home each day fasting in the morning and two hours following their evening meal. Participants also kept a written log of these blood sugars. In addition to the written log of blood sugars, the blood glucose monitors were equipped with a digital dated log of blood sugars, and these were downloaded into a data management system each time the participants attend a group care visit and at the final MUCA interview. To improve consistency and compliance in blood glucose monitoring, study participants were sent a reminder text/verbal message twice daily (one at 7 am each morning and again at 7 pm each evening) to remind them to check their blood sugar.

All materials generated for recruitment, interviews, and surveys were checked for readability using a Gunning Fog Index evaluation (Gunning Fog Index, n.d.). The Gunning Fog Index ratings for the recruitment letter, pre-participation screening questionnaire, MHLCS questionnaires, passport to wellness cards, and partner interview questions ranged from 6.36 to 9.1. The consent forms received a Gunning Fog Index rating of 10.5 for readability due to the required University of Georgia and University of North Georgia protection clauses which must be included verbatim on the consent forms. Without the protection clauses, the Gunning Fog Index rating for the consent forms was 9.8 (Gunning Fog Index, n.d.). I verbally confirmed and/or clarified each study participant's understanding of the consent forms prior to them signing their consents.

Interviews were audio recorded, transcribed by the researcher, and member-checked to ensure accuracy in transcription and freedom from researcher's personal interpretations. In addition, immediately following interviews and prior to transcribing, the researcher journaled impressions and thoughts about the interviews and interactions between MUCAs in field notes. Journaling helped further triangulate data while assisting in identifying researcher biases (Grbich, 1999; Stake, 2006). Field notes were based primarily on my observations and thoughts, thus they provided additional information for drawing inferences on participants behaviors and how those behaviors impacted their perspective (Maxwell, 2012).

All study participants were interviewed both initially before participating in the group care meetings and again one month following the completion of the six group care meetings. Adults were interviewed together as a single MUCA. The rationale for interviewing MUCAs together as a single unit was to illuminate the relationship between adult pairs while at the same time to examine the impact of that relationship on self-management of diabetes. The researcher spent two months conducting the initial interviews and an additional two weeks transcribing data.

Following transcription, each interview was member-checked with participants to ensure accuracy in transcription and interpretation. Member-checking is a means to ensure credibility of the study by verifying that transcriptions accurately reflect participants' experiences while at the same time reflecting multiple realities and voices of those being studied. Member checking involved having study participants review typed copies of audiotaped interviews to ensure accuracy of researcher in transcription (Polit & Beck, 2012). For this study, each study participant was provided with a typed copy of each interview and encouraged to review it for accuracy in transcription. Participants were encouraged to write any comments or corrections on

the typed copy and return them to the researcher for corrective editing. I asked all study participants if they read their transcripts, and although all participants confirmed that they read their transcripts, only two study participants returned their typed transcriptions for corrective editing. Both participants were part of the same MUCA pair and marked a name misspelled as the only corrective action in the transcription. As a result the misspelled name was corrected in the transcription prior to thematic analysis.

Once interviews were transcribed and member-checked, I conducted an initial thorough reading of each transcribed interview. I then reread my field notes. According to Manen (1990), "the aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful…" (p. 36). Thus, rereading each transcription and field note thoroughly immersed me in the data prior to beginning analysis.

Initially transcriptions were analyzed using thematic analysis. "Theme analysis refers to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work" (Manen, 1990, p. 78). Thematic analyses were conducted in two stages: (1) initial interviews were reviewed for emergent themes as one section of the analysis, and (2) post-participation interviews were reviewed for emergent and evolutionary themes as a second section of the analysis. Both analyses were then compared to review the themes. Lists of pre- and post-group participation interview questions are in Appendix E.

As suggested by Manen (1990) a detailed approach to isolating thematic statements was initially used to analyze participant interview data. This method involves a line-by-line reading of each interview transcription. After each sentence or sentence cluster I asked myself what this data revealed about the experience of diabetes mellitus in medically underserved co-residing

adults. I then went back and reread transcriptions using a selective approach to uncover themes. In this approach text is reread several times and essential statements or phrases which describe phenomena are highlighted (Manen, 1990). I completed this process of detailed isolation of themes followed by selective isolation of themes two times on each interview transcription. Once themes were identified, exemplar statements which supported identified themes were then organized under each theme.

Field notes were journaled immediately following each interview and group care meeting. These notes served as evidence of my impressions and potential biases in the interpretation of MUCA interactions as related to diabetes care and management. According to Grbich (1999), "…we need to know how the researcher thinks, acts, interacts with, and feels about the participants and her/his project, and how her/his concerns and values affect the data" (p. 89). Journaling or interviewer diaries help to ensure the honesty of the researcher and serve to reduce researcher bias in addition to providing valuable qualitative data about overall impression of participant interaction and learning (Grbich, 1999). According to Stake (2006), researchers involved in multiple case study analyses need reassurances of what they are seeing recorded as objective data, and so they triangulate their data to gain these reassurances. Triangulation of data in this study was enhanced by a personal journal of field notes as additional support of data collected (Stake, 2006).

<u>Data Analyses</u>

A sequential mixed methods approach was used to analyze initially the qualitative and then the quantitative data. Complementarity was achieved through a combination of analysis methods (Hesse-Biber, 2010). Complementarity involves using both quantitative and narrative data in combination to better understand a social story in its entirety (Hesse-Biber, 2010). This

facilitates a total understanding of lived experiences. Following analysis of qualitative data,

quantitative data was compared with qualitative emergent and eolutionary themes to both insure

accuracy in identifying themes as well as complete the picture of the lived experience of

medically underserved co-residing adults (MUCA) with diabetes.

Data were analyzed using several strategies to ensure a comprehensive picture of diabetes

self-management in MUCAs. As described above qualitative data collected in the initial

interview were reviewed multiple times and emergent themes were identified. Field notes from

the initial interviews were then compared with themes and my impressions were bracketed

alongside themes.   This process was then repeated for the post-participation interview data and

field notes. For the post-participation data, both emergent and evolutionary themes were

identified. Field notes from group care meetings were then analyzed alongside post-participation

interviews. This permitted a rich understanding of the lived experience of diabetes in MUCAs.

According to Whittemore et al. (2001), there are four primary criteria for conducting qualitative

inquiry; credibility, authenticity, criticality, and integrity. Repetitive review of data by the

researcher ensures integrity of the study by grounding my interpretations of the data through

multiple reviews of interpretations (Whittemore et al., 2001). In addition field notes provided

additional support of both integrity and criticality by recording initial impressions, observations,

thoughts and feelings about interviews and group care encounters.

Following the analysis of qualitative data, quantitative health data (MHLCS scores, weight,

BMI, waist circumference, and Hgb A1c) were evaluated with SPSS descriptive statistical

analyses. Descriptive statistics communicated information about the study group as a whole in

regard to health status. Following whole group statistical analysis, SPSS was then used to

examine quantitative data change over the course of the study both as whole group,

independently by participant, and then by MUCA pair. Quantitative data was then "qualitized" and used to support qualitative findings. "Qualitizing" is the process of analyzing quantitative data qualitatively (Sandelowski, 2000). According to Sandelowski (2011), "what largely differentiates inquiry is not whether it is qualitative or quantitative, but rather the attitude taken toward the data collected for or generated in a study" (p. 344). The purpose of this study was to gather a variety of data and synthesize it to develop a comprehensive understanding of the lived experience of diabetes and the impact of an innovative approach to health care and education in MUCAs. The quantitative data served to support the qualitative findings, thus "qualitizing" the statistical data "gave life to the patterns emerging in the quantitative analysis, to extract more information from the data and to aid in interpreting them" (Polit & Beck, 2012, p. 619).

According to Sandelowski, (2001), through translation of numbers to patterns, descriptive and inferential statistics can be used to provide a more complete picture of phenomena. "Qualitative themes are numerically represented in scores, scales, or clusters in order to more full describe and/or interpret a target phenomena" (Sandelowski, 2001, p. 231). For this study, quantitative health data were organized in such a manner to examine trends in numerical data and compare those trends with emergent and evolutionary qualitative data themes. For example, trends in MHLCS scores, weight, waist circumference, and HgbA1c changes were analyzed and compared to trends in qualitative themes. Using this method of triangulating data helped to provide a more complete answer to research questions. This is discussed further the in Chapter 4 of this dissertation.

Both qualitative and quantitative data were integrated into a case study analysis to evaluate the impact of MUCAs' participation in diabetes group care on ability to self-manage diabetes. According to Stake (2006), a case study analysis can often be complex, and thus is best

completed by one researcher collecting and analyzing data. It can be difficult to transfer the full experience of what is observed about a phenomenon through multiple minds into one cohesive description, thus Stake (2006) recommends that individual cases be analyzed by a single individual. In conjunction with the aforementioned recommendations, I completed all transcriptions, SPSS analyses, and syntheses of data for this study. Both qualitative and quantitative analysis methods and findings were reviewed with doctorally prepared healthcare researchers to ensure accuracy.

This chapter has presented the methodological approach used to study the lived experiences of medically underserved co-residing adults (MUCA) with diabetes. In addition a mixed methods approach was used to evaluate the impact of group care on self-management of diabetes in MUCAs. In the next chapter I will present the findings from the data analyses and discuss the implications of study results.

CHAPTER 4

RESEARCH FINDINGS AND DISCUSSION

Using a lens of hermeneutic phenomenology, in this section I will present the findings of this research study. Phenomenology is not just providing rich description. It also involves researcher interpretation, thus consistent with the tenets of hermeneutic phenomenology, findings will include my interpretation of data via thematic analysis in conjunction with the lived experience of medically underserved co-residing adults (MUCA) with diabetes.

According to Manen (1990) it is important to understand what phenomenology does and what it does not do. First, "phenomenology is not an empirical analytic science" (Manen, 1990, p. 21). True phenomenology does not collect and interpret data to determine who did what and to what extent, rather it goes beyond simple interest to provide a deeper understanding of a situation or event. "Phenomenology is not mere speculative inquiry in the sense of unworldly reflection" (Manen, 1990, p.22). It is grounded in real world lived experience, thus presentation of findings will include the actual statements made by participants and excerpts from my field notes describing the lived experience of diabetes in MUCAs. "Phenomenology is neither more particularity, nor sheer universality" (Manen, 1990, p. 23). It is the balance of interest in what is unique and interest in the universality of the experience that guides phenomenology. Thus, in this section I will present the findings in such manner as to illuminate the uniqueness of MUCAs, but also provide a real world picture of the universality of the experience.

I use my research questions as a framework to present study findings and discussion. I begin with an overview of the methodology I used to interpret data to answer my research questions, and then specifically I present each research question followed by the findings that

helped answer each question. Since I analyzed qualitative data initially via thematic analysis to determine emerging and evolving themes, I will present qualitative findings first followed by the quantitative findings that support or refute qualitative findings. For each question I present pertinent emerging and evolving themes. After presentation of the evidence which supports the five research questions that guided this study, I conclude the chapter with a personal reflection on the evolution of myself as a person, healthcare provider, and researcher. I use excerpts from field notes to illustrate the change in myself over the course of the study.

What is the Day-to-day Lived Experience of Medically Underserved Adults

Living with Type II Diabetes Mellitus?

Emergent Theme: *Complexity of Diabetes*

In the first research question my goal was to get a full description of the day-to-day lived experiences of the MUCAs with regards to diabetes. To get a fuller picture of the experience this question was posed to both adults in each MUCA at their initial interview prior to participation in group care. Qualitative analysis of these interviews revealed a theme, *Complexity of Diabetes,* in regard to the day-to day lived experiences of both participants diagnosed with diabetes and their co-residing adult partners. The *Complexity of Diabetes* theme highlighted the struggles of trying to manage diabetes when you are medically underserved. This theme is characterized by the numerous road blocks individuals with diabetes encounter when they attempt to gain knowledge and health care with limited access to services. As illustrated in the comments below diabetes affects multiple aspects of the lives of participants, such as finances, nutrition, intimacy, relationships, and mood. The *Complexity of Diabetes* theme emerged from the following responses by study participants:

"Having to take shots. Don't matter what you eat, you're not going to lose weight. You go without. Like I went without it and I just go without my medicine. Sometimes patient assistance will run into problems or they don't get your medicine in time and you just run out."-Participant 001A

"I don't know. It just means…a mess. It's a mess. That's about the way to describe it. It's a mess. Just that diet thing, because it used to be you could eat this and you don't eat this and now it's different and everybody needs to get on the same page. I don't remember to take my medicines. I remember them and say oh, I'll take them in a minute but then I get to doing something else and by the time I get to remembering to take them, it's time to take my bedtime medicines." –Participant 001B

"I mean I did do my medicines correctly and I did eat correctly. I did eat a little bit of sugar, but most of it I think….well one, I think for instance, is that my fingers were getting really sore. And then it was just like wanting to just be free from pricking my fingers for a little while. When we go out to eat we have to make sure that it is better for us than one of the others that are quick and easy and low cost. Um…I was lost. I had…I mean I knew a little bit about what my niece went through but being that her diabetes was type 1, it was totally different. Um… I think the care that I've been getting is limited…by moneywise. I think if we all had more money, we'd be able to get a better situation about what is going on and a little bit better care."- Participant 002A

"It's just you can't go by your normal daily routine without wondering what is wrong with you, if it is connected to that or something else. Like if it is connected to your diabetes or not. We were trying to do the healthier breads and stuff, and we were noticing a lot of the stuff was higher cost, and we were trying, and we're still trying to do better.

But when you're on a budget, you have to limit what you buy so you can't get as much of the better stuff. So you have to kind of lay it out so you can have food." –Participant 002B

"Fruits and vegetables are outrageous. You know it's like you can eat McDonald's all week for $10 as opposed to buying fresh meat and fresh fruit. And if you don't eat them right away they go bad so then you gotta buy more which gets even more expensive"- Participant 003A

"Yeah money because we can't afford insurance and he's self-employed. And even when you go to the doctor, like I went for my chest and they say well, here we will try this and see if it gets better before we start doing any tests since you don't have insurance so.." -Participant 003B

"Because of everything that you go through with your diabetes, um...it affects your intimacy. You have a lot of intimacy issues because of the fatigue that it causes."

"I have all of the questions. I have most of the answers. I just have to get the pieces of the puzzle to fit. But I'm having a hard time putting them in place. Where do they go? How do you get that corner piece and that middle piece to fit here without making that bottom piece pop? That's the best way I know to describe it. Most of the information I found out about diabetes, I researched myself. My husband and I got so health conscious. We did without potatoes, pasta, bread, anything white, we did not touch it for 30 solid days. Nothing. He lost three pounds. I gained six."- Participant 004A

"A lot of it is the financial stuff too – that creates a lot of stress." –Participant 004B

"It affects your sleep. It affects what you can and can't eat. It affects everything. Everything back until the time my mother and father been born...my grandparents...my granny lived to be 99. They ate stuff you're not supposed to eat all their lives and never got sick." –Participant 005A

"...there's information out there but you can't really find it. Like when you are trying to find out what you can eat, it says talk to your dietician, but if you don't have a dietician, and you try to research it and find something, there's not really anything out there. It's like they get the best of him at work and I come home and I get him sleeping all the time. And I know he's not feeling good. He's tired and we gotta get to the bottom of it so we can get our life back too. I just want my husband back (gets a little teary eyed)." –Participant 005B

In reviewing my field notes, the Complexity of Diabetes theme is reinforced by comments about study participants' words. The following excerpt from my first interview field notes with study participants 005A and 005B illustrate my initial impressions of diabetes management in my participants:

I feel there is a lot of confusion and misunderstanding on his (005A) part about diabetes, and as such diabetes has caused him a great deal of physical and psychological pain.

Quantitatively, the *Complexity of Diabetes* theme is supported by the initial health statistics collected on the study participants. Participants' initial Hemoglobin A1c (HgbA1c) and the equivalent average daily blood glucose for each HgbA1c level are listed in Table 4.1. In addition, each participant's initial Basal Metabolic Index (BMI) and its corresponding weight classification can be found in Table 4.1. Consistent with the literature, medically underserved

individuals with diabetes have a more difficult time managing their blood glucose and their

weight (Davis et al., 2008; Garcia-Huidobro et al., 2010; Rosal et al., 2011). Study participants

with diabetes initially presented with high HgbA1cs and BMIs. As previously discussed in

Chapter 3, HgbA1c > 6.5% is an indicator of uncontrolled blood glucose over a previous 90-day

time period. In addition research suggests that individuals with adult onset diabetes have a more

difficult time managing weight, and elevated BMI is positively associated with and increased

risk of developing complications from diabetes such as loss of eyesight or kidney impairment

(Diabetes Statistics - American Diabetes Association, n.d.). All study participants had an initial

BMI>30%, indicating a weight classification of clinical obesity. Quantitatively, Table 4.1 depicts

the Complexity of Diabetes theme discussed above by statistically showing how study

participants with diabetes historically have shown difficulty in managing their blood glucoses

and their weights.

Table 4.1
Pre-Group Participation HgbA1c and BMI for Study Participants

Participant	HgbA1c (%)	Average Daily Blood Glucose	BMI (%)	Weight Classification
001A*	7.2	156	61.1	Obese
001B*	8.1	183	45.1	Obese
002A*	9.0	210	67.8	Obese
002B*	7.0	150	32.7	Obese
003A*	9.1	213	35.0	Obese
003B	5.8	114	34.2	Obese
004A*	11.2	276	47.0	Obese
004B	5.8	114	30.6	Obese
005A*	7.7	171	33.1	Obese
005B	4.7	<90	37.7	Obese

indicates participants diagnosed with diabetes

How Does Participation in Group Care Health Visits Affect Health Locus of Control in

Medically Underserved Co-residing Adults (MUCA) Living with Type II Diabetes Mellitus?

Emergent Theme: The Importance of Social Support

The second question considered the effect of participation in group care on a MUCA's

health locus of control. Qualitatively this question is best answered by the theme *The*

Importance of Social Support, which emerged from the second interview data and was also

reflected in the field notes from group care meetings. This theme includes the idea of

normalization of diabetes through connectedness to other group members which in turn helped

participants engage with and feel more accountable to group members. Initially, *The Importance*

of Social Support theme was best evidenced by the following responses from study participants

during post-participation interviews:

> *"I think I do better with the group, like if we are in group I do better with my*
>
> *sugars and stuff. It's like you want to show people that's in the group that you can do it*
>
> *and if you can do it, they can do it."–Participant 001A*

> *"And you find that somebody might read something over here and then they might*
>
> *share it with the whole group. And then somebody else shares something else and it's*
>
> *like it really helps." –Participant 001B*

> *"Yeah, I mean I know they're out there, and I can text them to see how they're*
>
> *doing and they'll respond. So that helps." –Participant 002A*

> *"It was interesting to see the different types of people and what they do to help*
>
> *themselves. And you form a bond you know?...talking to people that have the same thing*
>
> *you have." –Participant 002B*

"For me, when I first got diagnosed, I was like Oh My God! I am like the only 17 year old with diabetes. But then hearing the other people…most of these people that were in group, I seen them out. I know them, and I didn't know they had diabetes." – Participant 003A

"I really liked the talking with other people because I don't really ever get that." –Participant 003B

"Mine was just knowing that there are other people out there who's diabetes is worse than mine. You know? Not saying that we're in competition, just knowing that…let me rephrase that…not that their diabetes is worse than mine, just that they are in the same boat as me, and they're struggling with the same things that I'm struggling with, you know?" –Participant 004A

"Not feeling alone. It just gives you that comfort when you have somebody else around. Plus when you are in group, no one can judge you because they're in the same boat as you." –Participant 004B

"Made me understand I wasn't the only one who had that kind of problem." – Participant 005A

"Hearing other people's stories about what they experienced and what they did – that was helpful." – Participant 005B

In reviewing my field notes, I discovered the following evidence which supported *The Importance of Social Support* theme:

I got the impression that these two participants enjoyed the socialization aspect of the interview. – excerpt from observational note Interview 1: Participants 004A & 004B

The participants seemed to enjoy this opening activity and even commented on similarities they had with other group members based on details shared in their introductions. –excerpt from observational note Group Care Meeting 1

Everyone in the group spoke at least one time during our discussion and several members asked questions which then prompted others in the group to provide answers. – excerpt from observational note Group Care Meeting 1

Participant 001A shared that she was having a particularly difficult week due to remembering her father who she unexpectedly lost to diabetes complications about one year ago. She blamed her inability to control her sugar on the fact that she was depressed about losing her father. Several of the other group members offered her support suggesting that she could do better with her diabetes. Following the group meeting, participants 004A, 004B, 001A, and 001B stayed about 10 extra minutes and continued discussing ways 001A could do better with her diabetes. This was not at my suggestion – this subgroup formed on their own to help 001A. – excerpt from observation note Group Care Meeting 2

The group continues to be supportive of each other and openly shares with each other. Each week I feel like my position in the group is changing from leader to group member. Although at times the group does look to me to clarify or validate their ideas and thoughts, they often will come up with solutions to their issues on their own as a group. – excerpt from observational notes Group care Meeting 3

My one highlight of the evening was when I witnessed participant 004A go over to 001A to speak with her privately after the group meeting. For me this is still evidence of the need for social support and the need for these group members to feel as though their

thoughts and reactions are valid. It seems to me that feedback from a person you have identified as similar to yourself has a bigger impact than advice given by a person with whom you have a more hierarchal relationship. – excerpt from methodological note following an outburst by one group member at Group Care Meeting 4

Quantitatively, the Multidimensional Health Locus Control Scale (MHLCS) provided some interesting evidence to answer the question of the effect of group care on health locus of control in medically underserved co-residing adults (MUCA). To review, Form C of the MHLCS, developed by Wallston et al. in 1989, deals specifically with an individual's belief about illnesses such as diabetes (Wallston, 1992). Form C of the MHLCS measures three components of health locus of control in regard to illness: (1) internal control, which refers to the degree to which the individual feels that he/she has control over the development and progression of illness; (2) chance, which refers to the degree to which an individual believes that illness is a result of chance in life; and (3) powerful others, which is the degree to which and individual attributes the development and progression of illness to and influential individual such as a partner or healthcare provider (Wallston & Wallston, 1981). Researchers suggest that individuals who are most successful at self-management of disease have a higher score on the internal control component versus the other two components, chance and powerful others (Athale et al., 2010; Grotz et al., 2011; Jacobs-Lawson et al., 2011; Schlenk & Hart, 1984).

For my study, Form C of the MHLCS was given to study participants at three different time periods: prior to participation in group care, after the third meeting, and six weeks following participation in group care. My rationale for the timing of the MHLCS was three-fold: (1) initially before participation in group care to establish baseline scores for each study participant; (2) midway through group care meetings to identify any early shifts in locus of control, if any:

and (3) six weeks following group care meetings to determine if there were any lasting shifts in locus of control following participation. See Table 4.2 for the means and standard deviations for the three categories of the MHLCS (internal, chance, and powerful others) over the course of the study.

Table 4.2
MHLCS Means and Standard Deviations Over the Course of the Study

	Course of Study					
Dimension of HLC	Pre-participation		After 3rd Meeting		Post-participation	
DM* (*n*=7)	*M*	*SD*	*M*	*SD*	*M*	*SD*
Internal	24.43	2.23	22.43	6.27	24.42	4.28
Chance	9.85	5.05	10.71	4.96	11.29	6.52
Powerful Others	20.86	3.27	21.00	5.69	22.43	3.21
NDM* (*n*=3)						
Internal	26.33	4.04	29.67	2.89	30.00	1.00
Chance	14.00	6.00	13.33	3.06	17.00	6.25
Powerful Others	25.33	4.51	26.33	5.13	27.00	2.65

*DM = diabetes mellitus, NDM = no diabetes mellitus

These results indicate that participants who did not have diabetes showed an overall increase in internal locus of control and powerful others from pre-participation to six weeks following participation in group care. These results were consistent with previous research using Form C of the MHLCS which showed that participation in group care increased internal locus of control in adults living with chronic disease (Athale et al., 2010; Grotz et al., 2011; Jacobs-Lawson et al., 2011). In addition, these results supported the theme *The Importance of Social Support.* If we consider the group members as powerful others as evidenced by participant comments above, then we naturally expect this component of the MHLCS to increase following participation in group care.

Interestingly, the chance subscale mean score showed a slight decrease (-.67) following the third group meeting and a subsequent increase (3.67) at six weeks post-group care

participation in participants without diabetes. I searched literature to find an explanation for this variance, but I found no supporting evidence. Despite the unanticipated variation in mean scores of the chance subscale, the overall increase in mean scores for the internal subscale (3.77) exceeded the increase in both the chance subscale (3.00) and the powerful others subscale (1.77). These results indicate that group care increased internal health locus of control more than external locus of control in study participants who were not diagnosed with diabetes.

Study participants with diabetes showed a slightly different result when comparing means across the study. Initially participants with diabetes had a high mean internal health locus of control score (24.43), that decreased slightly after the third group care meeting (22.43), and increased six weeks post-participation in group care (24.42). The mean score for chance increased from pre-participation (9.85) to post third group meeting (10.71), and again at six weeks post participation (11.29). The powerful others subscale mean scores also increased over the course of the study: pre-participation (20.86), post-third meeting (21.00), and six weeks post participation (22.43).

The slight decrease in mean internal locus of control scores between pre-participation and after the third group care meeting in individuals with diabetes was unexpected. These results may indicate one of the following: initially patients with diabetes began with a high score on the internal control component (M=24.43) and exposure to group care may have increased their beliefs about the effect of their social support systems on their ability to self-manage diabetes. This in essence might cause a slight decrease in internal control and an increase external locus of control (powerful others and/or chance). According to Wallston (2005), in review of literature assessing the validity and reliability of the MHLCS, in studies on individuals with chronic diseases, powerful others scores were higher in individuals with diabetes than individuals with

other chronic diseases such as rheumatoid arthritis. It is unknown why this variance occurs.

Interestingly, as shown in Table 3 above, powerful others scores increased from pre- to post-group participation in participants with diabetes. The increase in mean powerful others scores provides further evidence of the impact of social support on self-management of diabetes in MUCAs. Although mean internal locus of control scores decreased slightly in participants with diabetes following participation in three group care meetings, overall mean internal locus of control scores increased over the course of the study, suggesting that at the end of the study individuals with diabetes believed that their behaviors affected control of their diabetes.

What are the Effects on Self-management of Diabetes in Co-residing Adults Who Participate in a Group Care Model for Health Visits and Education?

Evolutionary Theme: *Inevitability of Diabetes* to *Diabetes is Bad But Preventable*

Qualitatively this research question was best answered by the evolution of the *Inevitabilty of Diabetes* theme elicited from initial interviews and field notes to the *Diabetes is Bad but Preventable* theme, as evidenced in the final interviews and field notes. In initial interviews, the *Inevitability of Diabetes* predominated participants' beliefs about their ability to manage and prevent complications of diabetes. The *Inevitablity of Diabetes* theme was characterized by a general belief in the study sample that diabetes is not necessarily a disease, but something that just happens in their family as people age. As a result, individuals don't recognize it as preventable and thus don't engage in behaviors to prevent worsening of their disease. Many participants vocalized familial experience with complications from diabetes including blindness, loss of limbs, and eventual death. The *Inevitability of Diabetes* theme is evidenced by the following statements from study participants:

"I didn't really think it was like a disease. It was just something Daddy had to have and if Daddy had to have it, we just took care of him. It's just something that happened because my grandparents on his side had it. I believe it just runs in your family. There's not fat to it or no skinny to it or whatever." -Participant 001A

"But a lot of doctors won't fool with you if you are diabetic. You know they can't…and you're overweight and diabetic, well just forget it you're gonna die anyways. I didn't think it was a big deal because everyone in my family dealt with it, you know?" – Participant 001B

"Sometimes it's overwhelming. Sometimes you just…well, recently I did give up. I just got tired of checking my sugar and not seeing anything change." –Participant 002A

"You think you know what difference it makes whether I eat this or not. I mean does this really make a difference?" – Participant 003B

"My mom was actually low and had low blood sugar, but my biological father had diabetes. Two of his sisters and one of his brothers and his mom all had diabetes. And his mom died of complications from diabetes. Some though don't just act any different. They just don't know what diabetes is and what it can do, I think. …but like most people don't go to the doctor in my family unless something really bad is wrong with them, and so they don't know." –Participant 003A

"Well my mother was diabetic and well, she had 13 brothers and sisters and all of them had diabetes. Then I have a sister that is diabetic real bad and I have another sister who is diabetic. So, it's my cousins from my momma's side you know, her brothers and sisters, at least one or two of every family is diabetic." – Participant 003B

"I watched that man go from 360 pounds to this and lose his feet, his ankles all because of diabetes. And because of his ignorance." –Participant 004A

"We told him he had it. He knew he had it but he still drank the Cokes, two liters at a time." –Participant 004B

"I just stubborn to the fact that if it's going to get me, it's going to get me. I ain't going to worry about it. I just try to be happy and do what I can until then. I don't know." –Participant 005A

In addition to patient comments in interviews, the *Inevitability of Diabetes* theme was also reflected in researcher field notes. The following excerpt from a pre-participation interview field note demonstrates how emotionally and mentally challenging the *Inevitability of Diabetes* theme was for me:

For me this interview so far was the most telling and the most emotionally trying. I think that is in part because Participant 004 A has been a patient of mine in the clinic for over 4 years. I have watched her struggle with her diabetes. I was the practitioner that hugged her when she burst into tears when she found out she was going to have to go on insulin. The answer that struck me the hardest in this interview was when I asked them both what diabetes meant to them 004 A answered, "It means death." It took every ounce of me not to cry when she said that.

Interestingly, the *Inevitability of Diabetes* theme evolved into a theme of *Diabetes is Bad But Preventable* from pre-interview data to post-interview data. As reflected in the following excerpt from a pre-participation interview field note, one of my desired outcomes for group care was to help patients understand that diabetes can be prevented and complications from diabetes can be avoided:

I am so disturbed by Participant 004A's comment about the meaning of diabetes that it challenges me to want the group care to work for these participants. I want so much to change that perception, but I don't know if I can make someone see that diabetes does not define them as a person. It is an illness, not a death sentence.

Initially I thought the evolution of the Diabetes is Inevitable to Diabetes is Bad But Preventable theme was influenced by my own underlying beliefs about the disease; however, in repetitive review of the pre- and post-interview data, I found evidence of this evolution each time I reread the transcriptions and organized common statements into collective themes. The following comments from post-participation interviews illustrate the evolution of *Diabetes is Inevitable* to *Diabetes is Bad But Preventable*:

"I still believe it is a death sentence. I seen too many people die from it. But in one way, and then in one way I'm like well, you live right and you do right, it won't be as bad." – Participant 001A

"I still think it is a sucky disease to get stuck with. It might be bad but I tell you what, I'm going to put up a fight." – Participant 001B

"Well, the... my biggest thing is seeing the numbers when I first started... That freaked me out. Oh yeah, um... when I went back home that just floored me. So I knew I had to do something. Uh...and it just gave me a kick in the butt but on top of it, losing a limb is important. But having control of the numbers is more on my mind than anything. Just having the right medicines to take and to be able to have those on top of controlling what you are eating. I don't know what it says about me as a person but it makes me feel better. Seeing the numbers down it makes me feel mentally better in addition to physically". - Participant 002A

"I guess something going wrong in my body like you know losing my vision. I mean you know some of that happens with age but you wonder is that something contributing to it? And you don't know if the diabetes is or not so that's something. And it's real important to take care of yourself." – Participant 002B

"I mean it still sucks. It sucks. I don't know. I'm hoping that with my daughter being so young and seeing what I'm going through that they can make health changes now so that it won't be a problem". – Participant 003A

"Well, my beliefs really changed when I lost my mom because she was going through a lot and she would say, well I'm going to die anyway so I'm going to eat what I want. Well, now I know that isn't so. I think now that I know that it is wrong not to watch what you eat and how much sugar is in food, take them steps on how to live longer. Don't just ignore it." – Participant 003B

"I know diabetes can be controlled. It can get out of control and it can be a death sentence, but it is all about what role I play in that." – Participant 004A

"I have changed a lot in the way I eat. Because before I would eat three or four glasses of tea. I still drink three or four glasses of tea, but now I use Splenda instead of sugar". - Participant 004B

"Well, have you heard about those things on the radio about the new pill you can take to better control your diabetes. You know something like that would be good. And to me, if they can do that then that's just a step closer to people not having to have diabetes. You know then maybe we can give that pill to our children, like a vitamin, and it can keep them from getting diabetes." – Participant 005A

In reviewing my field notes from post-participation interviews, I saw evidence that I had observed changes in study participants from my initial interview. One common observation I noted was the change in the response to my question, "What does diabetes mean to you?" Initially in pre-participation interviews I received many negative responses to that question including loss of limbs, loss of eyesight, and even death. In my field notes from post-participation interviews I found many responses by participants had changed. For example, the following excerpt from a post-participation interview illustrates my observed change in thought by study participants:

> One of the most surprising statements I heard in this interview was in response to my question, "What does diabetes mean to you?" Participant 004 A initially told me that diabetes meant death to her, but today she said she was not afraid of diabetes anymore. It was an illness that she could live very healthy with if she just kept her sugar under control. She admitted that she recognized that diabetes could cause her to die, but with some lifestyle changes and keeping her blood sugar under control, she could live with diabetes. I also noticed her demeanor was lighter in this meeting and she displayed confidence in her ability to self-manage her diabetes. I acknowledged the change I observed in her and began to question her further about what caused her to change her beliefs about diabetes. Her response was inspiring for me. She stated that she learned more about diabetes in the six group care meetings than she had ever known in her entire life. She commented that the input from other individuals who were in the same circumstances as her helped her believe she could manage her diabetes better. My initial thought about this interaction is joyful – had group care achieved what I had hoped it would? Did it make these individuals realize that you don't have to just get diabetes, lose

limbs and eyesight, and just die? It will not be until I transcribe this interview and my

other interviews and repeatedly review the transcriptions that I will be able to answer

these questions, but I am hopeful.

Each group care meeting was organized around a specific diabetes education topic; however, study participants' discussions drove the information that was presented. Each group care meeting also included a variety of activities designed to help participants improve self-management skills outside the healthcare setting. One activity in particular clearly reflected the effect of group care on self-management of diabetes in MUCAs. This activity entitled "Dear Diabetes Expert," gave group members the opportunity to provide advice to fictitious individuals who presented an issue related to diabetes. The activity was the focus of our fifth group care meeting. We were winding down group care meetings, and I wanted to ensure participants had internalized some tools which would help them self-manage diabetes at home. We began the activity by passing out cards which had a "Dear Diabetes Expert" letter printed on them. What study participants did not know was that each card incorporated an issue that each one of them had vocalized in either their initial interview with me or during a previous group care meeting. Once the cards were distributed I instructed group members to volunteer to read their card, and then we would take some time providing advice as the diabetes experts. The following excerpt from field notes scripted immediately after that meeting illustrate how participation in group care enabled individuals to identify solutions to previously identified issues with diabetes management:

It was fascinating to witness study participants offer advice and the many

different solutions they came up with for the issues. Everyone in the group voluntarily

participated in the activity. Both members with diabetes and without diabetes offered

sound advice that resonated much of the educational information presented and

discussed in previous meetings. Some even shared innovative approaches to the issues

that they tried in their own personal experiences. After the group meeting ended, six of

the group members stayed and additional 45 minutes to socialize and discuss the activity.

There is no specific quantitative data that directly reinforces the evolution of the

Inevitability of Diabetes theme to *Diabetes is Bad But Preventable* theme; however, the changes

in weight, HgbA1c, and waist circumference for each of the MUCAs are presented in Table 4.3.

Six out of ten study participants experienced a decrease in their weights, HgbA1cs, and waist

circumferences, including Participant 005A, who only attended four group care meetings. These

physical changes in study participants seems to coincide with and evolution in thought in these

study participants that the impact of diabetes is something they can change via lifestyle change.

Table 4.3
Changes in Weight, HgbA1C, and Waist Circumference by MUCAs

Participant	Weight (lbs)	HgbA1C (mmHg)	Waist Circumference (inches)
001A	11.00	1.20	.80
001B	-3.00	-2.90	-.50
002A	-23.00	-1.10	-5.00
002B	-3.80	-.20	-2.50
003A	2.60	-1.50	.00
003B	1.00	-.60	.50
004A	-5.80	-1.40	-4.10
004B	4.60	1.40	.80
005A	-7.00	-.20	-4.00
005B	-2.20	-.20	-1.30

How Does Having a Partner Participate in Group Care Impact Co-residing Adults' Ability

to Self-manage Diabetes Outside of the Care Environment?

Evolutionary Theme: *Diabetes is Scary* to *There's Hope for Diabetes*

The fourth research question concerned the effects of co-residing adults participating in

group care on the ability of the adult with diabetes to self-manage outside of the group care

setting. Qualitative data from the first and final interviews give evidence of evolution from an

intial theme of *Diabetes is Scary to There's Hope for Diabetes*. The *Diabetes is Scary* theme

emerged from the first interview data in which I asked each study participant, "What is your

biggest fear related to diabetes?" Each medically underserved co-residing adult (MUCA) pair

shared experiences in which they were exposed to complications of diabetes that frightened

them. Most of these experiences involved loss of limbs, loss of eyesight, or death from a

complication of diabetes. The *Diabetes is Scary* theme is evidenced by the following responses

by study participants:

"That it's [diabetes]gonna kill you." – Participant 001A

"Well, I had a doctor tell him that well you're a diabetic so most likely your

organs are all shutting down and you're overweight too so you know. It's just like saying

you're dead so go ahead and die cause we just don't need you on this earth anymore." –

Participant 001B

"Umm... I was lost. I had... I mean I knew a little bit about what my niece went

through, but being that hers was type 1 diabetes, it was totally different. So I really

didn't know what to expect...and it was scary." – Participant 002A

"I'd say it's internal damage which when you can't see it happening, you don't

know it's going on and you say well everything is okay. But then you see stuff on tv and

you go oh, well my eyes are doing this so maybe that's what it is. So I guess it's maybe

fear of what is going on in your body. Cause you can't see it." –Participant 002B

> *"And I worried about my daughter. My blood sugar would shoot up and I had to*
be on insulin like three times a day in the hospital, and they had to induce my delivery
because of my blood sugar staying up. I was really scared." – Participant 003A

> *"My mom, you know, she passed away from diabetes. It's scary you know?*
Seeing what she went through and having to worry about eating." –Participant 003B

> *"The most horrific thing I heard during my studying, trying to figure out what to*
do and how to test my sugar, what it's supposed to be and what causes it to increase, was
being told insulin is the bottom line kid. Once you start taking them shots, it's over. You
gonna start losing your limbs and all that good stuff. And I was terrified. At least with
cancer you know that there's remission. There's a possibility of a cure with the
remission of cancer. But with diabetes, I'm sorry but nobody has taught me anything
different, but with time and progression, diabetes just gets worse and worse and worse. I
don't think diabetes ever gets better." –Participant 004A

> *"You know my father had diabetes, and I see my father in me…it scares the hell*
out of me because he had cancer." –Participant 005A

> *"My biggest fear is his declining health. You know maybe losing a foot or a limb.*
You know I'm going to be the primary care giver and I don't want to sound selfish but I
want him healthy to be there to help me." –Participant 005B

The *Diabetes is Scary* theme evolved into *There's Hope for Diabetes* in the final

interview data. This theme is characterized by a sense of increased awareness of management

strategies which improve the way participants feel and make them feel hopeful and empowered

about their futures. Evidence which supports this theme is in the following responses given by study participants in their final interviews:

"I don't really think there will ever be a cure for diabetes. I think that there might be something that's gonna control it. I'm not sure there will ever be a cure." – Participant 001A

"I think like I come in and change something then the next one will change something. I can come on in and get on down to each of us eating right one day."– Participant 001B

"With the progress and the medicine you just told us about, they're always coming up with something so I think …I don't know if I'll be around to see a cure but I'd like to. I'd like to see that happen." – Participant 002A

"I did like the recipes and finding out about eating more fiber and that it actually helps. I didn't realize that, and now I actually look at that and say, oh boy it's got fiber and I can process it better." – Participant 002B

"I mean it still sucks. It sucks. I'm hoping with my daughter being so young and seeing what I'm going through that she can make health changes now so that it won't be a problem."

"It's a horrible disease but it's manageable."–Participant 003A

"Well my beliefs really changed when I lost my mom because she was going through a lot and she would say well I'm going to die anyway so I'm going to eat what I want. Well now I know that isn't so. I think now that I know that it is wrong not to watch what you eat and how much sugar is in food, take them steps on how to live longer. Don't just ignore it." –Participant 003B

"You know it helped me with self-esteem and the whole diabetes is a death

sentence. I know that diabetes can be controlled." – Participant 004A

"Knowing what my sugar is now, I can say yeah I have diabetes, but I can live

healthy too." – Participant 004B

Quantitative descriptive statistical data suggests that including a co-residing adult in

group care has a beneficial effect on the self-management of diabetes outside the healthcare

arena. As shown in Table 4.3 above, the comparative changes in health statistics of the

medically underserved co-residing adult (MUCA) pairs were impressive. Overall 60% of study

participants experienced a decrease in their weights, HgbA1cs, and waist circumferences over

the course of the study. In addition, adults within each MUCA overall experienced similar

changes in their health statistics; however in two of the MUCAs (001A/001B and 004A/004B)

changes in adult health statistics varied. 001B and 004A both decreased their weights, HgbA1cs,

and waist circumferences, but 001A and 004B increased all three health statistics.

It is difficult to predict why some participants were able to improve their health statistical

data while others increased their weights, HgbA1cs, and waist circumferences. In reviewing

group care field notes, I noticed that I recorded observations about 001A and 004B in particular,

after several group care meetings. Listed below are observation notes made specifically about

participants 001A and 004B following group care meetings:

001A shared that she was having a particularly difficult week due to remembering

her father who she tragically lost to diabetes complications about one year ago. She

described her inability to control her sugar on the fact that she was depressed about

losing her father. – excerpt from group care meeting 2

001A commented that she could not exercise due to her degenerative back disease and the fact that she weighed over 300 pounds. – excerpt from group care meeting 3

001A outwardly attempted to dominate the conversation by discussing her long list of medications and how none of them work. – excerpt from group care meeting 4

At one-on-one session with 004B he expressed concern over being diagnosed with diabetes this evening. I explained to him that I wanted to meet privately with him after group tonight to discuss getting him started on medications. He declined stating that he did not want to go on medications right now because it might cause him to lose his truck driving job. – excerpt from group care meeting 5

These observations seem to suggest a lack of desire in participants 001A and 004 B to acknowledge their own role in how diabetes impacts their lives. Literature suggests that individual motivation to change and belief in their ability to manage diabetes is crucial to health improvement (Schillinger et al., 2009; Tillotson & Smith, 1996). In conjunction with the literature on diabetes self-management, I suggest that 001A's and 004B's lack of improvement in their health statistics resulted from a lack of desire to acknowledge the impact of diabetes on their lives and their lack of desire to change. The following comments by participants 001A and 004B made in final interviews support my suggestion:

"I would get up in the morning and my sugar is like 84 or 82 and that is when I would go have a doughnut or some Oreos. I have been eating them like every other day."- Participant 001A

"I have gotten lazier. I was busy and anything could have happened. It's just an excuse, okay? And everyone can make up an excuse for whatever reason." – Participant 004B

Interestingly, 003A increased her weight, decreased her HgbA1C, and showed no change in her waist circumference. 003B also increased her weight, decreased her HgbA1c, and showed a slight increase in her waist circumference. It is possible that the weight increase in this MUCA pair was attributable to different clothing worn at weigh in visits, but also this variance may suggest that 003A and 003B were actually building muscle mass, which weighs more than body fat. Muscle mass was not measured in this study, so true measurement of muscle mass change was not available.

<u>What is the Relation Between Health Locus of Control and Physical Weight, Body Mass Index, Waist Circumference, and Hemoglobin A1c?</u>

Emergent Theme: *Diabetes Behavior Can Change*

In the final research question I tried to understand the relationship between health locus of control and participant's health statistics. The ideal answer to this question is statistical analyses to evaluate this relationship is a correlational analysis; however, due to the small number of participants (*n*=10) it was impossible to run this test. According to Cohen (1988) a minimum sample size of 30 is needed to run correlational statistical analyses.

Qualitatively, this question is answered through responses made by study participants in the final interviews. The responses listed below reflect the emergent theme, *Diabetes Behavior Can Change*. This theme emerged from final interviews when I questioned study participants about how they benefitted from group care meetings. The theme is characterized by voices of hope and pride in small changes they made in their lives. Both participants with diabetes and without verbalized specific lifestyle changes they had made since participating in group care and how it made them feel better and more capable of managing diabetes themselves.

"I've been trying to walk my dog more. We don't go too far, but we walk. And I feel stronger after I do that. I try to walk a little further each time" – Participant 001A

"I don't buy the sweet stuff anymore, so sweet stuff is out of the house. If we want something sweet we eat a piece of fruit. And I can tell we are doing better." – Participant 001B

"I love to look at the label and like Mom said, look at the fiber My sugar has been much better since I started choosing food with more fiber. And I feel proud of myself for that." – Participant 002A

"I have been trying to cut my portion sizes, only one serving you know and more vegetables. And so I guess I'm losing weight and that's great because I don't feel hungry." – Participant 002B

"We're eating better. We don't eat as much red meat and my husband and daughter are helping. We are walking more, and I feel much more in control of my diabetes." – Participant 003A

"I am just more aware that diabetes can just hit you and through this meeting I learned what to do so that situation doesn't come up." – Participant 003B

"My knowledge on diabetes has improved and I feel good about reading labels and exercising and my sugar is better." – Participant 004A

"We have more control, and I'm eating different now too." – Participant 004B

"I learned a lot because I was able to touch the tools in group care and you would tell us to go home and try it. The only way I can learn to do something is to give something to me and to touch it. Then when it gets repetitive that stays with me forever." – Participant 005A

"I really understood the Hemoglobin A1c after the pin cushion and the pins

demonstration. I never understood what that number meant. I just knew it wasn't good if

it was high, but now it makes sense that if there's too many sugars on my hemoglobin

than there won't be enough room for the oxygen I need to get to all my organs and I just

won't feel good. That really helped me to understand why I have to be careful about

what I eat and getting exercise. It really helps." – Participant 005B

In looking at the trends in descriptive quantitative statistics from this study some

interesting findings emerge. In reviewing statistical means in Table 4.2, in participants who did

not have diabetes both internal and external health locus of control increased over the course of

the study. In comparing the increase in internal locus of control with changes in BMI, weight,

waist circumference, and HgbA1c (Table 4.3) in patients without diabetes, Participant 005B lost

weight, lowered HgbA1c, and decreased waist circumference. Participant 003B gained weight,

decreased HgbA1c, and increased waist circumference. For participants with diabetes, overall

internal locus of control decreased and external locus of control increased. Five of the seven

participants with diabetes experienced a decrease in weight, HgbA1c, and waist circumference,

and Participant 001A and 003A both had a slight increase in their weights and waist

circumferences. These mixed results suggest that there may be a correlation between health locus

of control and weight, BMI, HgbA1c, and waist circumference, and that correlation is with

individuals with high internal locus of control or high influence of powerful others may be more

apt to improve their self-management of disease. This study's findings are consistent with

previous evidence of health locus of control and management of diabetes (Beverly & Wray,

2008; Clancy et al., 2007; Davis et al., 2008; Edelstein & Linn, 1985; Grotz et al., 2011;

Klomegah, 2006; Norman, Bennett, Smith, & Murphy, 1998; Sullivan et al., 2005; Tillotson &

Smith, 1996; Wallston, 2005). However, further investigational studies with larger samples of this population are necessary to establish this correlation.

For example, the body mass indices (BMI) for all study participants at the first group care meeting after the final interviews six weeks following group care meetings are presented in Figure 4.1. Six participants decreased their BMIs over the course of the study, indicating they experienced a body fat decline as a result of lifestyle modifications. The mean reduction in BMI across study participants was 2.74%, with a high of 11.6% to a low of 1.7%. Four study participants experienced increases in their BMIs, ranging from an increase of .2% to 1.9%.
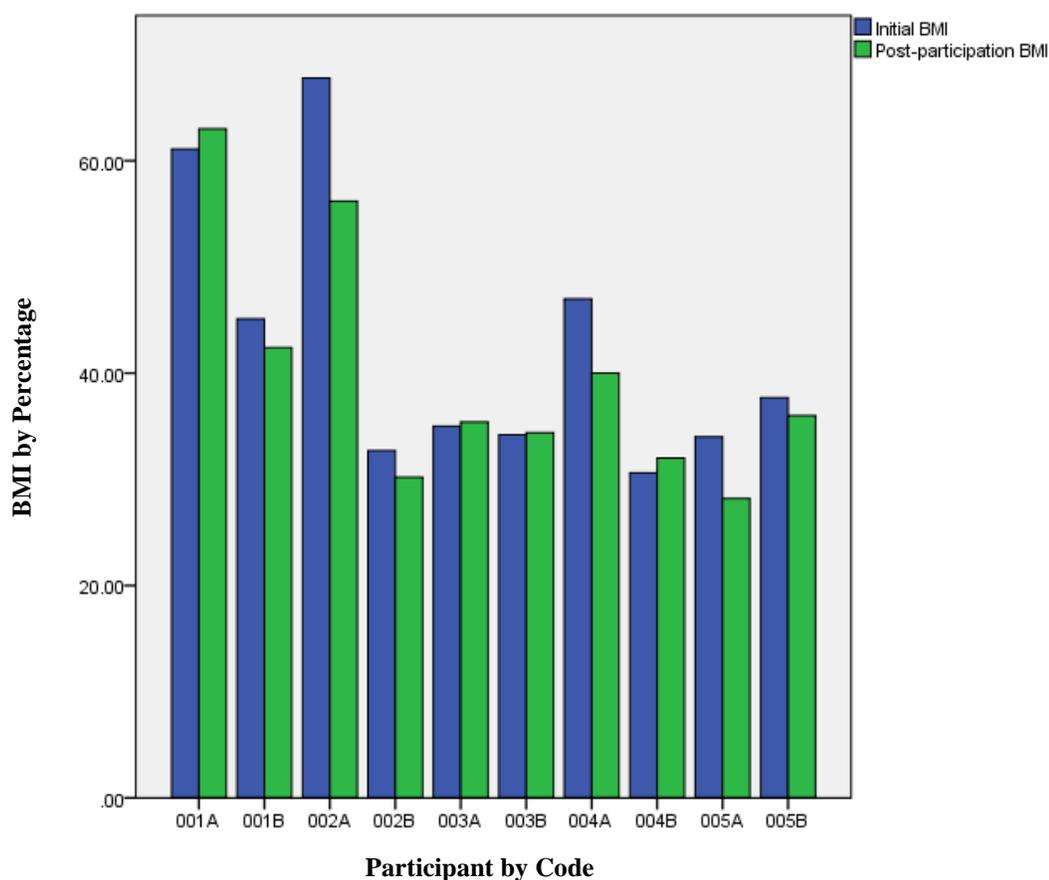

Figure 4.1: Body Mass Index Summary by Participant

Results also indicated that a majority of participants decreased their weight, HgbA1c, and waist circumference over the course of the study. As shown in Table 4.4 below, the biggest change was noted in participants' weights which had a mean loss of 2.56 pounds over the course of the study. The largest portion of weight lost was 23 pounds by Participant 003A. Three study participants gained weight over the course of the study: Participant 001A gained 13 pounds, Participant 004B gained 0.6 pounds, and Participant 004B gained 4.6 pounds.

Eight study participants experienced a decrease in their HgbA1c percentage. Two study participants had an increase in their HgbA1c: Participant 001A increased 1.2% and Participant 004B increased 1.4%. In addition, eight study participants experienced a decrease in their waist circumferences. Participant 003B had a 0.5 inch increase in waist circumference, and Participant 004B had a 0.8 inch waist circumference increase over the course of the study. The overall means and standard deviations for study participants' changes in weight, HgbA1c, and waist circumference are presented in Table 4.4.

Table 4.4
Average Participant Change in Weight, Hgb A1c, and Waist Circumference Across Group Means and Standard Deviations

	Changes Over Course of Study	
Health Statistic	*M*	*SD*
Weight	-2.56 (lbs)	8.97
HgbA1c	-.55 (%)	1.23
Waist Circumference	-1.53(in.)	2.21

In addition to the results presented above, participants with diabetes who were monitoring their blood glucose twice daily during the six weeks of group care, continued to do so following the group care visits. During the six weeks of group care participants with diabetes were sent reminder text and/or voice messages twice daily to remind them to check their blood sugar with the blood glucose monitor. Review of blood glucose monitor digital and written logs reveals that participants were accurately checking their blood sugars each time they received a reminder phone text or voice message.

For the six weeks between the end of group care meetings and the final interviews with participants, no reminder text or voice messages were sent to study participants to remind them to check their blood sugars. Review of digital blood glucose logs for the six weeks following group care visits until the final interview meeting revealed that participants with diabetes continued to check their blood sugar twice daily despite not receiving reminder text message or voice mails from the researcher to do so. The only participant that failed to continue to check his blood sugar as advised was Participant 004B, who was diagnosed with diabetes at the fifth group care meeting. He admitted in the final interview that about two weeks prior to the interview he lost his blood glucose machine and was too embarrassed to contact the researcher to request a new machine. This resulted in him failing to continue to check his blood sugar twice daily during the last two weeks prior to the final interview. He was subsequently given a new monitor following the last interview and restarted checking his blood sugar twice daily as instructed.

As illustrated above these results indicate that group care can influence behavior change and improve self-management skills in individuals with diabetes. Through knowledge acquisition and reinforcement via the group care environment study participants were able to

employ behavior and lifestyle changes which resulted in improvement in their diabetes self-management.

My Personal Evolution During Research

My personal journey in this research has been marked by much laughter, frustration, enlightenment, sadness, and joy. When I first decided to learn about the lived experience of medically underserved co-residing adults (MUCA) with diabetes I did not realize how much this research would change me as a person, a healthcare provider, and a researcher. I am a white woman of ordinary ability who has grown up "privileged." I have never had to question whether I would have food, shelter, love, or access to healthcare. I have never had to make the choice of paying my mortgage or paying for food to feed my family. I have also been fortunate to exist on this earth for 47 years without the burden of a chronic disease like diabetes. In fact, I have only been hospitalized three times in my life for the healthy, uncomplicated births of my three children. I don't worry about affording medications necessary to save my life, nor do I worry about seeing a healthcare provider when I need one. However, I am a realist and understand that on any given day I could lose the privileges I have and be forced to navigate life as a medically underserved individual.

Friends, colleagues, and family members who have heard me talk about the complexities of delivering healthcare to medically underserved families often ask me what draws me to keep working with this population. In reflection of this research study, I would say, innately I feel the need to care for those who do not have the same healthcare privileges as myself. I believe that if healthcare is to improve in this country it has to be accessible to all, thus as a healthcare provider I must find ways to reach those with limited or no access to healthcare services. To reach the medically underserved requires creativity, and through this research study I was able to examine

the effectiveness of an innovative model of delivering care to medically underserved adults living with diabetes. The Centering in Care model historically has shown positive outcomes in delivering prenatal care to women with high risk pregnancies; however, it only recently has been used to examine effectiveness in delivering care to patients living with chronic disease (Centering Healthcare Institute, n.d.). My research study afforded me the opportunity to add to the body of literature on the effectiveness of the Centering in Care model in chronic care treatment and education.

Personally I have grown in my beliefs about human behavior and human connection. This research gave me the opportunity to connect with my patients on a deeper level than I ever have in my past clinical experiences with them. Human connection is what drove my participants to attend group meetings and engage with others. Human connection made participants feel accepted, and it "normalized" diabetes for them. Human connection is also what made participants open to learning and gave them the courage to try something new in regards to diabetes. Human connection helped my participants trust in each other and themselves. Sharing this experience with this group of individuals and learning more about how they view and experience the world, has changed me, both as a healthcare provider and a researcher.

According to Manen (1990), "the problem with phenomenological inquiry is that our common sense, pre-understandings, our suppositions, assumptions and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question," (p. 46). Initially, my pre-understandings, and suppositions encouraged me to react every time I had conversations with study participants. For example, in my initial interviews I noticed that I would frequently

utter reassurances such as "good" or "okay, tell me more," even before I gave the participant the opportunity to continue speaking or not. I even commented frequently in my early field notes that my major concern was to collect information in a manner that did not cause additional stress for my study participants. The following excerpt from my field notes of a pre-participation interview illustrates this point:

> *While interviewing I often gave reassurances to both study participants. Part of me feels like this particular action was because I could sense their uncertainty about what to share coupled with my own desire to protect these participants. I don't think the reassurances were necessarily a bad tactic, but I do think overuse of them may influence how the participants responded.*

> *My relationship with these participants outside of this study appears to impact how I relate to them and talk with them during the study. I feel within myself this overwhelming desire not to injure them, as I consider these participants already so injured by not having adequate access to healthcare. I know this is a personal bias of mine and I know it affects how I ask questions and how I encourage the participants to keep conversing with me.*

I realize in reviewing my data, that one of the major driving forces for me was this overarching responsibility I felt to protect my participants even before I really "heard" their stories. Interestingly, my latter field notes and post-participation interviews show that as I spent more time with study participants and listened more, I evolved from this stance of protector to a more active listener role. And as I relinquished the self-imposed role of protector, I realized I was able to more clearly hear patient stories and how diabetes had affected their lives without superimposing my own personal thoughts on them and the impact of diabetes on their lives. The

following excerpt from the last two group care meeting field notes most clearly reflects the growth in me personally:

I struggled with how I handled 004b's diagnosis tonight and his unwillingness to be treated at this point in time. Part of me feels like I should have pushed harder with him and the other half of me feels like it is wrong to force someone to do something that does not fit within their world. I hope through tonight's activity that we have set the foundation for these members to be able to self-manage at home. - Group Care Meeting 5

As I reflect back on this last group meeting, I realize that it is not just my participants who have changed; I have changed as well. By releasing my fears of protecting this group and letting the group openly share and the group dynamics evolve, a community of support developed. These participants connected, problem-solved, and internalized methods for coping with diabetes that fit their unique experiences. I, in turn, was able to let go of some of my preconceived notions about this population. For example, I was able to let go of this idea that these individuals have been harmed and that I needed to protect them. This allowed me to really hear that these individuals, much like any person, have had some hard times, but with resources that fit their life circumstances they can problem solve and take care of themselves. They are not anomalies. They are simply human beings wishing to be heard, understood, and respected for their views of the world. – Group Care Meeting 6

These final two meetings exemplified my growth as a provider and a researcher. I was not the group leader, and I did not instantly react. I let the conversation evolve through the members' comments, and I listened. More importantly I heard them. Learning the art of hearing helped me grow as a researcher because hearing made me pause and reflect throughout this study.

According to Hesse-Biber (2010), "reflexivity is key at all points in the research process" (p.189). As noted above in my field notes, hearing individuals permitted me to let go of my preconceived ideas and reflect back on what was actually being said. As a provider, learning to really hear participants helped me to focus on what their actual needs were, and what they wanted from me as a provider. Hearing helped me tailor care to fit individual participant needs.

As a researcher this study provided me the opportunity to learn how I best study the world. I have always labeled myself a people watcher. I truly enjoy watching people interact. I also love the story of people's lives. I grew up in a family of storytellers, and it was through story that my family shaped me and helped me grow.

"Just as the body needs to breathe, our soul requires the fulfillment and expansion of its existence in the reverberations of emotional life," (Dilthey, 1985, p. 59). It is no surprise to me that I was initially drawn to hermeneutic phenomenology for this study. My whole life had revolved around listening to the stories of my family and deriving meaning from those stories. What did surprise me was how using the mixed-methods approach for this study provided even richer and more complete answers to my research questions. Through this study, my doctoral courses, and much guidance from my doctoral committee mentors, I grew in my ability to understand the intricacies of a mixed methods design. According to Hesse-Biber (2010), one reason to choose a mixed methods approach is to achieve complementarity, "utilizing both quantitative and qualitative data to understand the social story, allowing the researcher to gain a fuller understanding of the research problem," (p.26). Complementarity was achieved in this study through a mixed methods approach.

Working with my doctoral committee members and the Human Development and Family Science faculty at the University of Georgia also influenced tremendous growth in me as a

researcher. I was fortunate to have worked with scholars who appreciated my creativity and desire to do things outside of the norm. Through their mentorship and feedback during this process I have learned that to be a good researcher you cannot be afraid to step outside boundaries. A good researcher stays committed despite unexpected hurdles and boundaries. Good research is marked by exhaustive collection and review of data until you reach saturation, the point at which your data repeats itself and nothing new emerges. And despite attention to every detail, good researchers learn to anticipate the unexpected and acknowledge that every study is marked by limitations and flaws that lead to future endeavors.

CHAPTER 5

STRENGTHS, LIMITATIONS, AND RECOMMENDATIONS

As previously mentioned this study examined the impact of group care on the self-management of MUCAs living with diabetes. In this final chapter I restate the research problem, and provide a discussion of the strengths and limitations of this study. In addition I conclude with recommendations for future research and implications for heathcare practice.

Diabetes is currently the sixth leading cause of death in Georgia (CDC - US Data & Trends Redirect - Diabetes DDT, n.d.). It is estimated that by the year 2030, over 50% of the US population will have diabetes if prevention strategies and education about diabetes remains unchanged (CDC - US Data & Trends Redirect - Diabetes DDT, n.d.). Diabetes is a devastating disease but even more devastating for individuals who lack access to healthcare, the medically underserved. Currently approximately 25% of the individuals living in the US lack access to healthcare (Schoen et al., 2011). This makes management of a disease like diabetes a daunting task because medically underserved do not receive the ongoing care required to keep blood sugar controlled. Many have labeled medically underserved as non-compliant due to their inability to afford the routine care visits and treatments required to keep their blood sugar controlled; however, researchers suggest that with appropriately tailored care with interventions that meet individual and family needs, medically underserved populations can effectively self-manage chronic diseases like diabetes (Garcia-Huidobro et al., 2010; Lewin, 2005; Rosal et al., 2011).

As explained in Chapter 2, in this study I attempted to develop a comprehensive picture of the lived experience of medically underserved co-residing adults (MUCA) living with diabetes. Through a mixed methods design I used the tenets of hermeneutic phenomenology

with descriptive quantitative data trends to identify themes that exemplify the lived experience of MUCAs and the impact of group care on self-management of diabetes outside the healthcare arena. I spent three months interviewing and facilitating group care for study participants.

Results of the study suggest that diabetes management in medically underserved adults is complex for both the individual diagnosed with diabetes and the supporting co-residing adult. In both initial and post-participation interviews MUCAs expressed challenges and difficulties in managing diabetes which include: lack of access to regular care, financial burden of monitoring and treatment, lack of consistent, usable information. Interestingly, findings indicate that both behavioral and mind-set change are possible, and a group care type format is a beneficial method for improving self-management skills in medically underserved populations. The findings of this study provide strong support for future research on innovative methods of delivering healthcare to serve marginalized populations. Legitimacy of the study findings was enhanced through multiple methods of data collection to form a synergistic comprehensive story of the lived experience of medically underserved co-residing adults living with diabetes.

For me this study was informative from both a scholarly and a professional standpoint. As a scholar, this study provides interesting foundational knowledge to guide future research. As indicated by the results presented, group care may serve as an effective means for improving self-management skills in medically underserved families coping with diabetes. As evidenced by this study, group care affected both internal and external health locus of control in study participants which led to an overall increase in the ability to self-manage diabetes outside the healthcare setting. Through qualitative data participants expressed the benefits of the group care environment – social support, normalization of diabetes, learning from others in similar circumstances, and desire to do better. Group care provided a non-threatening environment in

which both individuals with diabetes and their self-identified home support partners could freely express their concerns and frustrations without feeling judged. In addition having the provider sit within the circle as a group member and facilitate versus occupy a traditional leadership role empowered individuals to self-identify solutions to complex issues with diabetes management such as: food consumption, blood glucose monitoring, and medication adherence. This increased accountability of the group which was expressed in the qualitative findings and reiterated in the quantitative data trends of change in body weight, BMI, waist circumference, and HgbA1c.

As a researcher, group care provided the opportunity to learn the patient's story. By allowing the group to determine the topic for conversation and invoke their own stories of challenges and successes, the researcher is able to gain a more comprehensive picture of the challenges of self-management of diabetes in medically underserved populations outside the healthcare setting. By allowing group care participants to vocalize their own issues and formulate their own solutions, it provides for a more patient-centered approach to treatment versus the traditional healthcare provider directed plan of care.

Research indicates that individuals with chronic disease such as diabetes are better able to adhere to treatment guidelines when the plan of care involves the patient and family in the design process and is tailored to meet the individual needs of the patient and the family (Garcia-Huidobro et al., 2010; Philis-Tsimikas & Walker, 2001; Rosal et al., 2011). The findings of this study support the literature in that a majority of the study participants changed or improved self-management behaviors which improved their overall health profile in relation to diabetes.

<u>Limitations of the Study</u>

Generalizability of this study is limited due to the relatively small sample. Although difficulty in recruitment was anticipated, use of a convenience sample from a clinic at which the

researcher practices was thought to have yielded a larger number of participants. Individuals who refused to participate expressed a general mistrust of research and a fear of losing potential access to disability benefits if their health improved as a result of participation in the study.

Another limitation of the study was my potential bias due to my previous health care provider relationship with some of the study participants. Six of the ten participants had a previous patient-healthcare provider relationship with me. These six patients receive healthcare at the Appalachian Nurse Practitioner Clinic and have been patients of mine for the last two to five years. As a result, I was privy to these participants' beliefs, attitudes, and general behaviors prior to engagement in this study. For this study it was necessary for me to clearly identify my role to properly manage my emotions and feelings. In conjunction with the literature several strategies were implemented to insure that the data collected remained as free from researcher bias as possible. These strategies included verification of all data collected, self-reflective researcher field notes, and multiple reviews of data collected over time (Grbich, 1999). In addition, multiple data sources were used to secure a complete account of the lived experiences of participants (Creswell, 2012; Stake, 2006).

A final limitation of this study was time. Ideally, this study design lends it to a longitudinal format to study impact and change over longer than a three month period of time. Richer data could potentially emerge if I had conducted the study over a year with group care meetings scheduled monthly. In addition by increasing the study length to a year, it would be easier to compare the data from group care to traditional one-on-one clinic visit care due to the fact that the time intervals between group care visits and traditional clinic visits would be more congruent. However, considering the difficulty in recruitment, engaging in a year-long study would be difficult without implementing some different strategies to increase participation.

<u>Recommendations for Future Research</u>

This study serves as an interesting pilot for future inquiry. To my knowledge this is the first study to analyze the impact of group care and education on medically underserved co-residing adults (MUCA) living with diabetes. As suggested by the literature, an individual's family has a huge influence on how a person develops and manages chronic disease (Alverson & Kessler, 2012; Edelstein & Linn, 1985; Safyer et al., 1993; Thompson et al., 2001). For this reason, more studies are needed to address the impact of diabetes on medically underserved families. As illustrated by this study, group care models provide an effective means of studying groups of individuals.

Future research is warranted to look at the impact of group care longitudinally in medically underserved populations. A major challenge in delivering care to medically underserved individuals is increasing access to care while preventing financial burden to healthcare facilities which provide services to this population. In a traditional one-one-one care approach, healthcare practitioners are generally allotted a 10-15 minute block of time to see an individual patient. Group care provides an effective means for delivering cost-effective preventative care to medically underserved individuals. In a 90-minute meeting a healthcare provider can deliver care and education to 16-20 individuals using a group care approach. More research is needed to compare the financial costs of delivering care with a group care approach as compared with traditional one-on-one care.

More research is needed to compare patient outcomes of group care versus traditional one-on-one care with respect to chronic disease treatment. Research indicates adherence to traditional clinic visits in medically underserved populations is low (Schoen et al., 2011). Findings from this study showed that group care fostered adherence to care visits due to the

reported social support participants vocalized. More research is needed to assess whether group care is more productive than traditional care in visit adherence.

Traditional research with group care has focused on group care with individuals (Brown & Marfell, 2005; Clancy et al., 2008; Davis et al., 2008; Partiprajak et al., 2011). This study provided an interesting perspective by including adult pairs in the group care. Preliminary results of this study indicate that the influence of co-residing adults who participate in group care can have beneficial effects on self-management of diabetes outside the healthcare setting. While it is difficult to predict whether or not this type of effect would occur across different partnerships and individuals, it is an area that warrants continued and further investigation. Additional studies which compare group care with individuals versus adult pairs longitudinally are needed to provide additional evidence on which style of group care is most beneficial in treating a chronic disease such as diabetes.

To my knowledge this study is also the first mixed methods design used to evaluate the effectiveness of group care. Future studies which include both qualitative and quantitative data are needed to increase a more complete understanding of the impact of group care on self-management of diabetes. Incorporating data such as frequency of "sick" visits and number of emergency room visits could add evidence to the effectiveness of group care. In addition, studies which extend this model to other chronic diseases such as hypertension, hyperlipidemia, and obesity could provide more evidence to support increase of self-management skills in families living with chronic diseases.

<div align="center">Implications for Practice</div>

This study provided interesting insight for healthcare providers. Providing healthcare to medically underserved is a major initiative of the US government, and more than ever before,

healthcare providers are being challenged to increase access to care and improve quality of care for medically underserved individuals. Group care is an innovative method that affords providers and efficient and effective means of reaching this population. Providers can deliver care to 16-20 individuals in a 90-minute period of time. At the same time the group care approach allows for comprehensive education and treatment with patients as active partners in developing their healthcare regimens. As suggested by this study, the active participation of individuals in developing their healthcare plans leads to better self-management of diabetes outside of the healthcare arena.

On a personal note, as a healthcare provider, I found the group care method to be a more satisfying method of delivering care. By including participants as active partners in collecting health data and tailoring treatment strategies, I felt more confident in my participants' abilities to self-manage their diabetes. This confidence, in turn, led to less provider frustration over how to effectively reach individuals with diabetes. As a healthcare provider group care afforded me more opportunities to witness and share in my participants' successes in diabetes self-management while at the same time developing a new understanding about which tools work best for each individual. Group care also afforded me more time to creatively problem solve with my patients. This time led to greater personal satisfaction for both me as a provider and for my participants.

<div align="center">Final Comments</div>

I want to conclude this study with the words of Florence Nightingale, "So never lose an opportunity of urging a practical beginning, however small, for it is wonderful how often in such matters the mustard-seed germinates and roots itself" (Nightingale & McDonald, 2001, p. 36). We are living in a day and age of healthcare revolution in the US, and now more than ever before

we have the opportunity to reach individuals and families who have previously due to socioeconomic status been prevented from receiving basic health preventative and maintenance education and service. If we can effectively reach these individuals early with education and treatment which promotes health and wellness, we may in effect prevent the development of a chronic disease such as diabetes. The Centering in Care model is a unique approach to delivering preventative healthcare. Through this study I have shown how use of this model increased medically underserved co-residing adults' abilities to self-manage diabetes outside the healthcare setting. I hope to continue to develop innovative methods for delivering care to the medically underserved, and I realize that only through true understanding of the nuances of chronic disease in this population is true caring possible.

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APPENDIX A

GLOSSARY

Adult – any individual, male or female, age 18 – 70 years of age.

Centering in Care Model – "a model of group healthcare, which incorporates three major components: *assessment*, *education*, and *support*. Group participants meet with their care provider and other group participants according to a regular schedule for a much longer period of time (usually 90-120 minutes) than a usual check-up visit. Centering promotes individual health empowerment and community-building" ("Centering Healthcare Institute," n.d.).

Diabetes – (aka Type II Diabetes, Adult-onset Diabetes) a metabolic disorder characterized by the inability to regulate one's blood sugar as diagnosed by one of the following criteria: fasting plasma glucose $\geq$ 126, Hgb A1C $\geq$ 6.5%, and/or oral glucose challenge test (OGTT) $\geq$ 200.

Fasting Plasma Glucose (FPG) – a plasma glucose level obtained through finger stick after at least 8 hours of fasting by person.

Hemoglobin A1C (HgbA1C) - A minor component of hemoglobin to which glucose is bound. Measurement of HbA1c is a useful indicator of how well the blood glucose level has been controlled in the recent past and may be used to monitor the effects of diet, exercise, and drug therapy on blood glucose in patients with diabetes. In healthy people without diabetes, the HbA1c level is less than 7 percent of total hemoglobin. Also known as glycosylated or glucosylated hemoglobin (Diabetes Statistics - American Diabetes Association, 2011).

Medically uninsured/underserved – Individuals who have no medical insurance, do not qualify for government healthcare programs such as Medicare/Medicaid, and/or carry catastrophic health insurance but can't afford primary healthcare services.

Medically underserved co-residing adults (MUCA) – Two adult individuals, age 18-70 years, who reside at the same property and have limited access to healthcare services or are medically uninsured.

Partner – defined as two adults residing at the same residence who participate in the study. This could include married partners, same sex partners, co-residing partners, and dyads such as parent-child and sibling-sibling**.**

Random Blood Glucose (RBG) – a blood glucose measure obtained via fingerstick irrespective of fasting of a person.

APPENDIX B

RECRUITMENT FLYER

The Effects of Centering in Care on Self-management of Type II Diabetes in Medically Underserved Adults

If you or another adult residing in your home have been diagnosed with Type II Diabetes, you may qualify to participate in a research study. The purpose of this research is examine how the Centering in Care Model affects medically underserved adults living with type II diabetes mellitus.

For more details, please ask your healthcare provider or
call Carolynn DeSandre at 770-881-0630.

This research study entitled, "The Effects of Centering in Care on Self-management of Type II Diabetes in Medically Underserved Adults," is being conducted by the University of Georgia. Carolynn DeSandre is the co-Principal Investigator and is conducting this research under the guidance of Dr. Charlotte Wallinga, Associate Professor, contact number: (706) 542-4889; email: cwallinga@fcs.uga.edu. For additional information please contact: *The Chairperson, Institutional Review Board, University of Georgia, 629 Boyd Graduate Studies Research Center, Athens, Georgia 30602; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu.*

APPENDIX C

RECRUITMENT LETTER

Dear Interested Community Member,

My name is Carolynn DeSandre. I am a graduate student from the University of Georgia. I am also a certified Family Nurse Practitioner in Georgia. In conjunction with the University of Georgia and the University of North Georgia and under the direction of Dr. Charlotte Wallinga, I am conducting a research study entitled, "The Effects of Centering in Care on Self-management of Type II Diabetes in Medically Underserved Adults." The purpose of this research is examine how the Centering in Care Model affects medically underserved adults living with type II diabetes mellitus.

You are eligible to participate in this research if you are between the ages of 18 and 70. You must also have another adult living with you who is willing to participate in the study. This research is being conducted with men and/or women and who live at the same residence. Please do not participate if you are younger than 18 or older than 70. Women who are pregnant or are planning to become pregnant should not participate in this study.

As a participant, I will ask you to participate in the following activities:
- Two interviews with you and your partner. We will talk at two different times during the research. I will ask you questions about your life with diabetes. I am especially interested in learning how you self-manage diabetes at home. You do not have to answer any questions that make you feel uncomfortable. These talks will be audiotaped. You will be allowed to review them to make sure they are correct.

- Six weekly group care sessions. Each of these meetings will last approximately 90 minutes. If you have diabetes, you will be checking your blood sugar twice daily. A blood sugar monitor will be provided to you at no charge. In addition, I will be sticking your finger for blood at your group visits. All lab work is free for you and your partner.

- Three written surveys. You will also be completing a written survey at three points during the research. Your information will be confidential. Your name will not appear on any research materials.

As a token of my appreciation for participation in this study each adult partnership who completes all group care visits and interviews will receive a $25 gift card to Walmart.

If you would like to participate in this research study, or if you have any questions please call me at **770-881-0630**. If I do not answer, please leave a message with your name and telephone number where I can reach you. You may also contact Dr. Charlotte Wallinga at (706) 542-4889 or via email at cwallinga@fcs.uga.edu.

Questions or concerns about your rights as a research participant should be directed to The Chairperson, University of Georgia Institutional Review Board, 629 Boyd GSRC, Athens, Georgia 30602; telephone (706) 542-3199; email address irb@uga.edu. In addition, research at the University of North Georgia that involves human participants is overseen by the Institutional Review Board. Questions or problems regarding your rights as a participant should be addressed to Dr. Teresa Fletcher, IRB Chairperson, Department of Clinical Mental Health Counseling, 228 Barnes Hall, Dahlonega, GA, 30597, telephone (706) 864-1444, e-mail address IRBchair@ung.edu.

Thank you for your interest in this study. Please keep this letter for your records.

Sincerely,

Carolynn A. DeSandre, MSN, CNM, FNP-BC

APPENDIX D

CONSENT FORM

I agree to take part in a research study titled "The Effects of Centering in Care on Self-management of Type II Diabetes in Medically Underserved Adults," *conducted by* Carolynn A. DeSandre, Human Development and Family Science, University of Georgia, 770-881-0630. This study is *under the direction of* Dr. Charlotte Wallinga, Human Development and Family Science, University of Georgia, 706-542-4899. *My participation is voluntary. I can refuse to participate at any time. I can stop taking part at any time without giving any reason, and without penalty or loss of benefits to which I am otherwise entitled. If I decide to withdraw from the study, the information that can be identified as mine will be kept as part of the study and may continue to be analyzed, unless I make written request to remove, return, or destroy the information. My decision to participate or not to participate in the study will have no effect on the services I receive from the Appalachian Nurse Practitioner Clinic.*

The purpose of the study is to look at how the Centering in Care Model affects medically underserved adults living with type II diabetes mellitus. My participation in this study will last approximately three months.

The benefits that I may expect from it are: <u>possible</u> increased awareness about diabetes self-management. This <u>may</u> result in the following:
- o improved blood glucose control,
- o improved self-monitoring skills,
- o weight loss,
- o decrease in blood pressure,
- o improved physical activity levels,
- o improved dietary habits.

For study participants who are not diagnosed with diabetes, there is <u>possible</u> increased awareness of diabetes. This may result in <u>possible</u> improvement in diet and physical activity.

If I volunteer to take part in this study, I will be asked to do the following things:

- I will complete a telephone pre-participation screening to determine if I can participate in this study.
- I and my partner will be interviewed together to get our thoughts about diabetes. This interview will take approximately 90 minutes. It will be audiotaped and transcribed by the researcher. I and my partner will review the transcription for accuracy.
- If I have diabetes, I will be given a blood glucose monitor at no charge to me. I will have daily fingersticks to collect one drop of my blood. In addition I will have fingersticks at group meetings. These tests will monitor my blood sugar level. These tests are no cost to me, and results will be shared with me during my care visits.

- I will come to six weekly group care sessions with my partner, each lasting approximately 90 minutes. Each session will focus on one diabetes topic. Each meeting will include 60 minutes of group education. Following group education, I will meet with a nurse practitioner for approximately 5 minutes with my partner. The nurse practitioner will discuss my plan of care during the 5 minutes.
- At the beginning of each meeting the nurse practitioner will help me collect the following information:
    - o height (first session only),
    - o weight,
    - o blood pressure,
    - o pulse,
    - o Hemoglobin A1C (first session and one month following study only) and
    - o random blood glucose.
- If I have diabetes, I will be given a blood glucose monitor. I will be taught how to check my blood sugar with the monitor. I will check my blood sugar at home each morning before I eat and two hours after my last meal. I will keep a written log of these blood sugars. In addition the monitors are able to keep a dated log of blood sugars. These will be downloaded into a computer each time I come to a group care visit. I will be sent a reminder message via cell phone twice daily to remind me to check my blood sugar. All of these supplies will be provided to me free of charge.
- I will complete a written Multidimensional Health Locus of Control Scale (MHLCS) at three points during the study:
    - (1) initially before beginning classes;
    - (2) midway through participation after the third group meeting; and
    - (3) one month following the completion of the classes.
- One month following the end of group care meetings, I and my partner will have a final interview about diabetes. This interview will take approximately 90 minutes. This interview will be audiotaped and transcribed by the researcher. I and my partner will review the transcription for accuracy.
- If I and my partner complete all components of the study, we will receive a $25 gift card to Walmart.

The discomforts or stresses that may be faced during this research are:

- Minor discomfort related to fingersticks for blood glucose screening during study.
- Should I experience any unforeseen discomforts, I should contact Carolynn DeSandre immediately at 770-881-0630 and report the experience.

My confidentiality in participating in this study will be protected in the following manner:

- o *The data will be labeled with a code that the research team can link to idvidually-identifiable information. The key to the code will be secured in a locked container (such as a file cabinet or drawer) in a locked room. The coded data will be maintained in a different location.*

- o *The only people who will know that I am a research subject are members of the research team. No individually-identifiable information about me, or provided by me during the research, will be shared with others, except if necessary to protect my rights or welfare (for example, if I am injured and need emergency care); or if required by law.*
- o *Any information that is obtained in connection with this study and that can be identified with me will remain confidential unless required by law.*
- o *Coded data and code keys will be destroyed 5 years following the study by the principal investigator by shredding all coded documents.*

The researcher will answer any further questions about the research, now or during the course of the project, and can be reached by telephone at: 770-881-0630.

My signature below indicates that the researchers have answered all of my questions to my satisfaction and that I consent to volunteer for this study. I have been given a copy of this form.

_____   _____   _____
Name of Researcher   Signature   Date
Telephone: (770)- 401-1015
Email: cadesandre@gmail.com

_____   _____   _____
Name of Participant   Signature   Date

Please sign both copies, keep one and return one to the researcher.

Additional questions or problems regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 629 Boyd Graduate Studies Research Center, Athens, Georgia 30602; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu.
In addition, research at the University of North Georgia that involves human participants is overseen by the Institutional Review Board. Questions or problems regarding your rights as a participant should be addressed to Dr. Teresa Fletcher, IRB Chairperson, Department of Clinical Mental Health Counseling, 228 Barnes Hall, Dahlonega, GA, 30597, telephone (706) 864-1444, e-mail address IRBchair@ung.edu.

APPENDIX E

PRE-PARTICIPATION SCREENING QUESTIONNAIRE

ID Code:_____

This screening will be completed via telephone with researcher asking questions.

Directions: Please answer the following questions on your own without consulting your partner.

1. Have you and/or your partner been diagnosed with diabetes?
   o Yes, I have been diagnosed with diabetes. How long ago?_____
   o Yes, my partner has been diagnosed with diabetes. How long ago?_____
   o No, I have not been diagnosed with diabetes
   o No, my partner has not been diagnosed with diabetes

2. Have you or your partner attended a formal group education class on diabetes in the last 5 years?
   o Yes, I have attended a formal group education class on diabetes in the last 5 years
   o Yes, my partner has attended a formal group education class on diabetes in the last 5 years
   o No, I have not attended a formal group education class on diabetes in the last 5 years
   o No, my partner has not attended a formal group education class on diabetes in the last 5 years

3. Do you and/or your partner own a cell phone?
   o Yes, I own a cell phone. Phone number:_____
   o Yes, my partner owns a cell phone. Phone number:_____
   o No, I do not own a cell phone
   o No, my partner does not own a cell phone

4. I know how to use the following features on my cell phone: (Check all boxes that apply)
   o Receive a text message
   o Receive a voice message
   o I do not have texting capability on my cell phone
   o I do not have voice mail on my cell phone

5. (For participants diagnosed with diabetes) Do you know how to check your blood sugar?
   o Yes
   o No
   o

6. Are you between the ages of 18 and 70 years of age?
   o Yes (Please give your date of birth   _____)
   o No

7. Do you and your partner live at the same home or property?
- o Yes   How Long?_____
- o No

8. FOR WOMEN ONLY: Are you pregnant or do you plan to become pregnant in the next 6 months?
- o Yes
- o No (if no, please give the date of your last menstrual cycle _____)

Demographic Data:

Age:_____   Gender: ___Male   ____Female

Race:

___White (not Hispanic or Latino)

___Black or African American (not Hispanic or Latino)

___Hispanic or Latino

___Asian (Not Hispanic or Latino)

___Native Hawaiian or Other Pacific Islander (not Hispanic or Latino)

___American Indian or Native Alaskan (not Hispanic or Latino)

___Two or More Races (Not Hispanic or Latino)

Define your relationship to your partner: ___Married   ___not Married
                                               ___Parent/Child   ___Siblings

APPENDIX F

INTERVIEW QUESTIONS

(pre-participation interviews)

Interview Questions	Collected Data
1. **As you know I am conducting a study to gain insight and understanding on the impact of diabetes on a family, so I would like to begin by asking you to tell me about yourselves and how you became aware that one (or both of you) had developed diabetes?**	• **Partner Interviews**
2. **What things did you both experience that made you think something was going on?**	• **Partner Interviews**
3. **What made you decide to seek professional care?**	• **Partner Interviews**
4. **When were you diagnosed?**	• **Partner Interviews**
5. **What were your initial thoughts when you found out about diabetes?**	• **Partner Interviews**
6. **Tell me about a typical day in your lives dealing with diabetes.**	• **Partner Interviews Field Notes**
7. **How have your lives changed since the diagnosis of diabetes?**	• **Partner Interviews** • **Field Notes**
8. **What does diabetes mean to both of you personally?**	• **Partner Interviews Field Notes**
9. **How has your diagnosis been impacted by not having medical insurance or government healthcare benefits?**	• **Partner Interviews Field Notes**
10. **How has diabetes impacted your family?**	• **Partner Interviews**
11. **How do you get information about diabetes?**	• **Partner Interviews**
12. **How did you learn about taking care of diabetes?**	• **Partner Interviews**
13. **What are your beliefs about diabetes?**	• **Partner Interviews**
14. **Do any of your relatives have diabetes? Who are they and what did you learn from them about diabetes?**	• **Partner Interviews**
15. **What is your biggest fear related to diabetes?**	• **Partner Interviews**

INTERVIEW QUESTIONS

(post-participation interviews)

Interview Questions	Collected Data
1. I'd like to begin by asking you how you have been doing since we last met – what has been going on and how have things been going?	• **Partner Interviews**
2. How has managing your diabetes been? Tell me what kind of things you are doing to keep your blood sugars down.	• **Partner Interviews**
3. How about your family? Have you noticed any changes in your family since participating in group care meetings?	• **Partner Interviews**
4. What are your thoughts about group care?	• **Partner Interviews**
5. What parts of group care did you find most helpful, if any, and why?	• **Partner Interviews**
6. What parts of group care did you not find helpful, if any, and why?	• **Partner Interviews** **Field Notes**
7. What did you like best about group care?	•
8. Describe how you would change group care if you were to change anything.	• **Partner Interviews**
9. What did you like least about group care?	• **Partner Interviews**
10. How would you define diabetes now?	• **Partner Interviews**
11. What is your biggest fear related to diabetes?	• **Partner Interviews**
12. Is there anything else you would like to tell me about diabetes or group care?	• **Partner Interviews**

APPENDIX G

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL QUESTIONNAIRE

(for participants with diabetes)

Instructions: Each statement below is a belief about your diabetes. You may agree or disagree with each statement. Beside each statement is a scale ranging from (1) strongly disagree to (6) strongly agree. For each item please circle the number that represents how much you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM.** Circle **ONLY ONE** number per item. This is a measure of your personal beliefs, so there are no right or wrong answers.

1=STRONGLY DISAGREE (SD)	4=SLIGHTLY AGREE (A)
2=MODERATELY DISAGREE (MD)	5=MODERATELY AGREE (MA)
3=SLIGHTLY DISAGREE (D)	6=STRONGLY AGREE (SA)

		SD	MD	D	A	MA	SA
1	If my diabetes worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my diabetes, what will be will be.	1	2	3	4	5	6
3	If I see a healthcare provider regularly, I am less likely to have problems with diabetes.	1	2	3	4	5	6
4	Most things that affect my diabetes happen to me by chance.	1	2	3	4	5	6
5	Whenever my diabetes worsens, I should consult a medically trained professional.	1	2	3	4	5	6

6	I am directly responsible for my diabetes getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my diabetes improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my diabetes is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my diabetes improves.	1	2	3	4	5	6
10	In order for my diabetes to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my diabetes is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my diabetes is what I do.	1	2	3	4	5	6
13	I deserve the credit when my diabetes improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following my healthcare provider's orders to the letter is the best way to keep my diabetes from getting any worse.	1	2	3	4	5	6
15	If my diabetes worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my diabetes will get better.	1	2	3	4	5	6

17	If my diabetes takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my diabetes improves.	1	2	3	4	5	6

*This form is adapted from Wallston's Multidimensional Health Locus of Control Questionnaire (Form C) (2005).

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL QUESTIONNAIRE

(for participants without diabetes)

Instructions: Each statement below is a belief about your health. You may agree or disagree with each statement. Beside each statement is a scale ranging from (1) strongly disagree to (6) strongly agree. For each item please circle the number that represents how much you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM.** Circle **ONLY ONE** number per item. This is a measure of your personal beliefs, so there are no right or wrong answers.

| **1=STRONGLY DISAGREE (SD)** **2=MODERATELY DISAGREE (MD)** **3=SLIGHTLY DISAGREE (D)** | | **4=SLIGHTLY AGREE (A)** **5=MODERATELY AGREE (MA)** **6=STRONGLY AGREE (SA)** | | | |

		SD	**MD**	**D**	**A**	**MA**	**SA**
1	If my health worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my health, what will be will be.	1	2	3	4	5	6
3	If I see a healthcare provider regularly, I am less likely to have problems with my health.	1	2	3	4	5	6
4	Most things that affect my health happen to me and/or my partner by chance.	1	2	3	4	5	6
5	Whenever my health worsens, I should consult a medically trained professional.	1	2	3	4	5	6

6	I am directly responsible for my health getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my health improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my health is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my health improves.	1	2	3	4	5	6
10	In order for my health to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my health is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my health is what I do.	1	2	3	4	5	6
13	I deserve the credit when my health improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following my healthcare provider's orders to the letter is the best way to keep my health from getting any worse.	1	2	3	4	5	6
15	If my health worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my health will get better.	1	2	3	4	5	6

17	If my health takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my health improves.	1	2	3	4	5	6

*This form is adapted from Wallston's, Multidimensional Health Locus of Control Questionnaire (Form C) (2005).

APPENDIX H

AMERICAN DIABETES ASSOCIATION 2013 GUIDELINES FOR

DIABETES EDUCATION AND TREATMENT

Glycemic, BP, and Lipid Control
- A1C: <7.0%*
- Blood Pressure: <140/80 mm Hg†
- Lipids: LDL-C <100 mg/dL (<2.6 mmol/L);‡ statin therapy for patients with MI history or
- aged >40yrs with other risk factors
- Glycemic Recommendations for Nonpregnant Adults With Diabetes
- A1C <7.0%
- Preprandial capillary plasma glucose 70–130 mg/dL (3.9–7.2 mmol/L)
- Peak postprandial capillary plasma glucose <180 mg/dL (<10.0 mmol/L; measurements
- should be made 1-2 h after the beginning of the meal)
    - • Individualize goals based on
        - o Age/life expectancy
        - o Comorbid conditions
        - o Diabetes duration
        - o Hypoglycemia status
        - o Individual patient considerations
        - o Known CVD/advanced microvascular complications

*More or less stringent glycemic goals may be appropriate for individual patients.
Individualize goals based on diabetes duration, age/life expectancy, comorbid conditions, known CVD or advanced microvascular complications, hypoglycemia unawareness, and individual patient considerations
†Lower systolic BP goals may be appropriate based on individual patient characteristics and therapeutic response
‡A lower LDL-C goal of <70 mg/dL, using a high dose of a statin, may be appropriate in persons withovert CVD
BP=blood pressure; CVD=cardiovascular disease; MI=myocardial infarction
Physical Activity
Exercise programs for those with type 2 diabetes should include the following:
- ≥150 min/wk moderate-intensity aerobic activity (50%–70% max heart
- rate), spread over ≥3 days/wk with no more than 2 consecutive days without
- exercise
- Resistance training ≥2 times/wk
    - • Evaluate patients for contraindications that would prohibit certain types of exercise
- before recommending an exercise program
- Eg, uncontrolled hypertension, severe autonomic or peripheral neuropathy,
- history of foot lesions, unstable proliferative retinopathy

Smoking Cessation
• Advise all patients with diabetes not to smoke or use tobacco products

Medical Nutrition Therapy
Medical nutrition therapy recommended for patients with type 2 diabetes or
- Weight loss for all overweight or obese individuals with or at risk for diabetes
  - Low-carb, low-fat calorie-restricted, or Mediterranean diets may be effective in the short term (up to 2 yrs)
    - With low-carb diets
  - Monitor lipid profiles, renal function, and protein intake (in nephropathy)
  - Adjust hypoglycemic therapies as needed
    - Physical activity, behavior modification are important components of weight loss programs and can aid in weight maintenance

Management of Diabetes With Medical Nutrition Therapy
Adjust mix of carbohydrates, protein, and fat to meet metabolic goals and
- preferences patient
- Monitor carb consumption to achieve glycemic control
- Limit saturated fat intake to <7% of total calories
- Minimize *trans* fat intake
  - Limit alcohol intake
- ≤1 drink/day for women
- ≤2 drinks/day for men
  - Supplementation with antioxidants is not recommended
  - Meal planning should include optimization of food choices to meet RDA/DRI for

Diabetes Treatment: Hyperglycemia
- Metformin
  o Preferred initial therapy (if tolerated and not contraindicated)
- Consider insulin therapy
  - With or without other agents at outset in newly diagnosed patients with markedly symptomatic and/or elevated blood glucose levels or A1C
  - Add second oral agent, GLP-1 receptor agonist, or insulin
  - If noninsulin monotherapy at maximal tolerated dose does not achieve or maintain A1C target over 3–6 months
  - Choice of pharmacologic therapy should be based on a patient-centered approach. Consider:
    - Efficacy
    - Cost
    - Potential side effects
    - Effects on weight
    - Comorbidities
    - Hypoglycemia risk
    - Patient preferences
  - Insulin therapy is eventually needed for many patients due to progressive nature of type 2 diabetes

Retrieved from the American Diabetes Association (2013).

APPENDIX I

SAMPLE GROUP CARE MEETING

Meeting 1: What is Diabetes?
I. One-on-one with Nurse Practitioner
II. Defining Diabetes
       A. American Diabetes Association Definition & Classifications
              1. Type I
              2. Type II
       B. Trends in the United States
              1. Risk factors associated with Diabetes
              2. Controllable versus non-controllable risk factors
III. Diagnosis & Treatment
       A. Symptoms of Diabetes
       B. Testing for Diabetes
              1. HgbA1C
                     (demonstration of how HgbA1C reflects glucose control)
              2. Random Blood Glucose & Fasting Blood Glucose
       C. Treatment for Diabetes
              1. Blood Glucose Monitoring
                     (demonstration of how to use blood glucose monitor)
              2. Review of Criteria for Reducing Risk of Diabetes Complications
IV. Take Home Assignment
          1. Blood Glucose Diary
          2. Weekly Food Log Diary
V. Questions

APPENDIX J

PASSPORT TO WELLNESS CARD

Passport to Wellness

ID Code:_____   Date:_____

Height:_____   Weight:_____
Basal Metabolic Index (calculate with chart):_____
Gender: Male or Female (please circle)
Blood Pressure:_____/_____   Left or Right arm (please circle)
Pulse:_____
Finger stick blood glucose:_____HGB A1C:_____
Concerns to discuss with provider today: