

“I’m going to work with the tools”: An Exploration of Diabetes Medication Adherence
in African Americans of the Southwest

by

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ABSTRACT

Nationally, African Americans suffer disproportionately from diabetes; with 13.2% of African Americans diagnosed with diabetes compared to 7.6% of non-Hispanic whites (CDC, 2014). Nearly one-half of all people with diabetes are non-adherent to their oral medications; adherence to insulin therapy was 60%-80% (Brunton et al., 2011; Cramer, 2004; Rubin, 2005). This study explored the question, “What mechanisms are associated with adherence to diabetes medication, including insulin, for African Americans in the Southwest?” Twenty-three people participated in the study; 17 participated in interviews and six participated in gendered focus groups. A community-based participatory research (CBPR) approach engaged the African American community as partners in research.

Major themes emerging from the data included illness perception, support, and the process of medication adherence. Acceptance of the diabetes diagnosis was imperative for medication adherence. Stigmatization of diabetes was salient in the recruitment process and as it related to mechanisms for adherence. Furthermore, many informants were not aware of a family history of diabetes before their own diagnosis. Four gendered emerging typologies were identified, which further illuminated major themes. Moreover, an eight-step process of medication adherence model is discussed. The researcher was able to identify culturally compatible strategies that may be extended to those struggling with medication adherence. The implications section suggests a set of strategies that healthcare providers can present to people with diabetes in order to increase medication adherence.

Keywords: African Americans, diabetes, medication adherence, illness perception

DEDICATION

I wish to dedicate this dissertation to my family and my God. I am appreciative for the support and encouragement of my family including my three adult children: Eric, Bryan, and Kathryn. However, my most profound appreciation belongs to my husband of 32 years, Mark Wardian, who “always knew I would get a doctorate” even though I am the first in my family to graduate from college. How did you know?

Finally, I wish to give acknowledgement to the Giver of all knowledge who asked me to consider “whatever is true, whatever is noble, whatever is right, whatever is pure, whatever is lovely, whatever is admirable—if anything is excellent or praiseworthy—think about such things” (Philippians 4:8). I am eternally grateful.

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Media

The Informant	Phoenix Soul
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Participant Incentive Providers

Novo Nordisk (pedometers)	Walgreens (gift bags)
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TABLE OF CONTENTS

	Page
LIST OF TABLES.....	vii
LIST OF FIGURES.....	viii
CHAPTER	
1 INTRODUCTION.....	1
Study Aims.....	5
Definition of Key Terms.....	7
2 BACKGROUND AND SIGNIFICANCE.....	10
Social Determinants of Health.....	11
Management of Diabetes.....	19
Complications from Uncontrolled Diabetes.....	20
The Conceptualization of Medication Adherence.....	22
Diabetes Medication Adherence.....	23
Resiliency Theory and Eco-systems Theory.....	34
Historical Context.....	42
Summary of Theoretical Frameworks.....	45
Purpose of this Study.....	46

CHAPTER	Page
3	METHODOLOGY.....48
	Research Design.....49
	Content Analysis.....65
4	RESULTS.....74
	Participant Demographics.....74
	Categories and Themes.....78
	Gender: Emerging Typologies for Black Females.....91
	Gender: Emerging Typologies for Black Males99
	The Process of Medication Adherence Model.....111
	Summary of Findings.....132
5	DISCUSSION.....136
	Practice Implications.....147
	Policy Implications.....162
	Limitations.....167
	Research Implications.....169
	Conclusions.....171
	REFERENCES.....176

APPENDIX	Page
A ASU IRB APPROVAL.....	191
B SCREENING QUESTIONS.....	193
C QUESTIONS FOR FOCUS GROUPS AND INTERVIEWS.....	196
D RECRUITMENT FLYER.....	199
E ASU INFORMED CONSENT: FOCUS GROUP.....	201
F ASU INFORMATION LETTER: INDIVIDUAL INTERVIEWS.....	204
MARICOPA INTEGRATED HEALTH SYSTEM (MIHS) IRB	
G APPROVAL.....	207
H MIHS INFORMED CONSENT: INDIVIDUAL INTERVIEWS.....	209
I MIHS INFORMED CONSENT: FOCUS GROUPS.....	211

LIST OF TABLES

Table	Page
1. Recruitment of Participants.....	58
2. Focus Group and Interview Sites.....	59
3. Female Participant Demographics.....	72
4. Male Participant Demographics.....	73
5. Female Participant Diabetes-related Information.....	74
6. Male Participant Diabetes-related Information.....	75
7. Condensation and Categories Derived from Data.....	76
8. Emerging Typologies for Diabetes Medication Adherent African American Women.....	89
9. Emerging Typologies for Diabetes Medication Adherent African American Men.....	98
10. Participant Strategies for Preparing for a Doctor Visit.....	111
11. The AIDES Method for Improving Adherence to Medications.....	155
12. Qualitative Clustering of Emerging Typologies by Attributes and Eco-system Level.....	162

LIST OF FIGURES

Figure	Page
1. Age-adjusted Percentage of People aged ≥ 20 Years with Diagnosed Diabetes, by Race/Ethnicity in the U.S., 2010-2012.....	11
2. Percentage of Arizona and National BRFSS respondents who reported that they were told they have diabetes in 2002-2010.....	12
3. Arizona - Percentage of Adults with Diagnosed Diabetes by Age, 1994 – 2010.....	13
4. Poverty to Income Ratio (PIR) and Rates of Diabetes in the U.S.....	15
5. Income Level and Rates of Diabetes in Arizona.....	15
6. Education Level and Rates of Diabetes in the U.S.....	16
7. Education Level and Rates of Diabetes in Arizona.....	17
8. Ecological Systems Framework.....	37
9. Triangulation of Qualitative Data.....	52
10. The Process of Content Analysis.....	66
11. The Process of Medication Adherence.....	109
12. Carrie’s Medication and Supplies.....	112
13. Lucy’s Bag of Medications and Supplies.....	120

Figure	Page
14. Integrative Model of Shared Decision Making in Medical Encounters.....	147
15. Stages of Change Characteristics.....	156

Chapter 1

INTRODUCTION

Traditionally, medication adherence has been viewed from a problem-orientation, deficit perspective focused on those who are non-adherent to medication. This approach has been useful in describing the scope of medication non-adherence and has facilitated understanding about why people do not take medication as prescribed. However, there are many people who take medication as prescribed and much could be learned from those people who, theoretically, have encountered similar barriers to adherence. In addition, there are cultural influences that support medication adherence in African American populations. Therefore, this study will engage in a shift from non-adherence as viewed through the lens of problem-orientation to adherence as viewed through resiliency. The lens of resiliency theory will focus on strengths exhibited by African Americans with diabetes who are adherent to diabetes medication(s).

Nationally, African Americans suffer disproportionately from diabetes; with 13.2% of African Americans diagnosed with diabetes as compared to 7.6% of non-Hispanic whites (CDC, 2014). Similarly, Arizona Blacks have diagnosed diabetes (16.2%) at more than twice the rate of non-Hispanic whites (8%) (Bass & Porter, 2011). Social determinants of health are related to higher rates of diabetes in African Americans; however, social determinants do not explain all of the disparity (Barr, 2008). Some health disparities have been associated with neighborhood effects, lack of insurance, and racial differences in access to quality health care (Barr, 2008; Luftey & Freese, 2005). These factors help explain the disparity in diabetes for African Americans; however, they do not change the fact that poor glycemic control is having a devastating effect.

In the U.S., uncontrolled diabetes is the seventh leading cause of death (Xu, Kochanek, Murphy, & Tejada-Vera, 2010). Complications from poor glycemic control include heart disease and stroke (Stratton et al., 2000; Turner et al., 1998; UKPDS, 1998), neuropathy (Li et al., 2010), nephropathy (Gorina & Lentzer, 2008), retinopathy (Zhang, 2010), and amputation (Gregg et al., 2014). These complications may be prevented or reduced if patients properly use medication(s) to control blood sugar (Breitscheidel Stamentis, Dippel, & Schoffski, 2010; Shenolikar et al., 2006a). Moreover, Lee, Balu, Cobden, Joshi and Pashos (2006) suggest that improved medication adherence could reduce healthcare costs by as much as 28.9%. Furthermore, Roebuck, Liberman, Gemmill-Toyama, and Brennan (2011) demonstrate that adherence to prescription medication reduces total healthcare costs by more than the cost of the drugs themselves. More specifically, Jha, Aubert, Yao, Teagarden, and Epstein (2012) linked increased diabetes medication adherence to less hospital use and an annual healthcare savings of nearly five billion dollars.

Medication is prescribed to 85.6% of people with diabetes (CDC, 2014; NHIS, 2010–2012). Yet, nearly one-half of people with diabetes are non-adherent to their oral hyperglycemic agents (OHA) (Brunton et al., 2011; Cramer, 2004; Rubin, 2005). Adherence to insulin therapy was 60%-80% and most patients admitted to missing an occasional dose (Brunton et al., 2011; Cramer, 2004; Rubin, 2005).

Self-management of diabetes through lifestyle changes and medication adherence are necessary for avoiding serious complications. Heisler, Faul, Hayward, Langa, Blaum, and Weir (2007) found that Blacks had poorer glycemic control, lower rates of adherence to medications, and more diabetes-related comorbidities than whites.

Knowing the reasons that people with diabetes reported for non-adherence is instructive; it suggests potential barriers that must be overcome by people who are adherent with their diabetes medication(s). This study will contribute to the existing knowledge by exploring mechanisms for overcoming known barriers to medication adherence such as financial costs, personal fears, and negative responses from loved ones and medical professionals, which can assist in guiding African American patients toward improved medication adherence and healthier outcomes.

By uncovering mechanisms used by African Americans with diabetes related to diabetes medication(s) adherence, specific strategies may be better understood, temporal ordering may be observed (Miles & Huberman, 1994), and then be extended to those who are struggling with diabetes medication(s) adherence. As the strategies come from within the African American community, cultural congruence is assured.

Furthermore, public health implications for uncovering mechanisms related to medication adherence along with the temporal ordering of those mechanisms (Miles & Huberman, 1994) have the potential to influence health messages and enhance effective communication with African American people with diabetes who need to take medication to avoid consequences related to poorly managed blood sugar. Creating positive messages for medication adherence based upon the strengths present in the African American community has the potential to reduce the rate and severity of complications due to poor glucose management in this population.

Moreover, resiliency theory will allow for exploration of internal and external qualities that enable people to experience insight and growth in the process (Hill, 2007). This person in environment, strengths-based approach is useful in uncovering culturally

grounded strategies already active in the African American community, which allows for culturally appropriate replication of those strategies for the benefit of others in the community.

Furthermore, this resiliency framework distinguishes protective mechanisms at four ecological levels including individual, family, community, and society. At the individual level, the focus was on processes associated with internalizing positive regard for self, increasing self-efficacy, and promoting internal locus of control (Hill, 2007). At the family level, processes that increase support, foster healthy social interaction, and strategies that actively encourage and assist African Americans with diabetes were uncovered (Hill, 2007). At the broader community level, the focus was on identifying the role of mediating structures, both formal and informal (e.g. church, workplace, healthcare team, neighborhood). Mediating structures can be defined as, “informal or formal groups at the family or community levels that offset or buffer the adverse consequences of threatening risk factors” (Hill, 2007, p. 87). The society level focused on understanding the social determinants of health (e.g. education, income, access to health care) affecting management of diabetes (Barr, 2008; WHO, 2010).

As is consistent with a community-based participatory (CBPR) research approach, the researcher intentionally viewed the African American community as the experts and sought input and advice from the community at every stage to facilitate quality, culturally grounded research (Castro & Gildar, 2013; Cornwall & Jewkes, 1995).

The qualitative research study collected data through gendered focus groups. A screening tool used to assess eligibility of potential participants through inclusion criteria and collect demographics and information known to be associated with the social

determinants of health.. The inclusion criteria included (1) Self-identified as African American or Black; (2) diagnosed with Type 2 diabetes; (3) currently on insulin therapy; and (4) adherent to their medication(s) as assessed by four questions in the Simplified Medication Adherence Questionnaire (SMAQ) (Knobel et al., 2002; Moritsky, Green & Levine, 1986). Three gendered focus groups were facilitated; there were two women's groups and one men's group with two participants in each.

In-depth individual interview questions were formulated to target diabetes medication adherence mechanisms and strategies used by African American men and women from varying demographics. Nine women and eight men were recruited for the individual interviews. The social determinants of health including education level, income, and access to health care are related to health disparities; therefore, participants were asked about highest education level, category of income, and insurance status. This information was used to stratify sampling to represent a wider range of income levels, educational attainment, and access to health care for participants.

The researcher utilized the lens of resiliency theory to uncover mechanisms and processes that lead to adherence to diabetes medication(s). Content analysis included inductive coding to allow themes and categories to emerge from the data. Member checking included sharing the findings with the community as a means of confirmability and to build trustworthiness into the study. The strength inherent in triangulation of data was achieved through focus groups, individual interviews, and member checking.

Study Aims

This study is guided by a main question, "What mechanisms are associated with adherence to diabetes medication(s), including insulin, for African Americans?" By

focusing on the resilient strategies, supports, and processes employed by African Americans with diabetes, the researcher was able to identify culturally compatible strategies and supports for diabetes medication adherence that may be able to be extended to others who struggle to take their medication consistently. This research project had two primary aims:

Aim 1: To examine what individual and broader environmental mechanisms are associated with adherence to diabetes medication(s) for adult African Americans with Type 2 diabetes.

Aim 2: To identify internal and external factors that enable African Americans with diabetes to go beyond adherence and to develop a broader understanding of the disease and how to manage it.

Innovation

The study is innovative in that previous studies of medication adherence have taken a deficit perspective. This study suggests that much can be learned from African Americans who are adherent with their diabetes medication(s) in spite of having similar obstacles as those who struggle with adherence. Since many barriers to medication adherence are already known, learning how African American people with diabetes have successfully overcome those barriers and navigated the risks and adversity associated with non-adherence can provide strategies and processes that may be able to assist others.

This study is an initial step in understanding medication adherence from the African American perspective and to detect what protective mechanisms related to adherence may need to be strengthened. Knowing “how” and “what” are important in the process of medication adherence. There are identifiable processes leading to adherence

that can be shared with patients as a way of providing a “road map” to guide them and reduce anxiety about the process. Understanding the process of adherence may help some to better engage in self-management and move forward rather than getting stuck in a non-adherence loop.

Definition of Key Terms

Adherence: Cramer (2004) defines adherence as “taking medication as prescribed and/or agreed between the patients and the health care provider” (p. 1219).

African American/Black: The Census (2010) defines “Black or African American’ as a person who has origins in any Black racial group of Africa” (p.2). For the purposes of this study, participants self-identified as African American or Black.

Community-based Participatory Research (CBPR): The researcher intentionally seeks input and advice from members of the local community to accurately represent ideas and views of the community (Castro & Gildar, 2013). Therefore, CPBR research seeks to include the community of interest at every stage and seeks to learn from the community how they perceive the question of interest and how the question can best be answered from within the community (Cornwall & Jewkes, 1995).

Compliance: The notion of *compliance* with medical treatment is a concept requiring a dominant medical professional and a dependent patient; the patient is expected to comply with the health care professional’s treatment decision (Trostle, 1988).

Concordance: This concept of places emphasis on the shared decision-making process between patient and health care professionals when making decisions about prescribing treatments (Horne et al., 2005).

Culture: “The set of values held by a community and its corresponding worldview” (Marsiglia & Kulis, 2009, p. 4). Hruschka (2009) further asserts, “Culture has inertia and that culture is to some extent shared” (p. 237).

Glycated hemoglobin (A1C): The American Diabetes Association (ADA; 2012) defines A1C as a blood test that measures average blood glucose control over the previous two to three months. It is expressed in terms of the percentage of glycated hemoglobin, or A1C, in the blood.

Health Care Providers (HCP): This term is broadly used to include a wide variety of healthcare professionals including, but not limited to primary care physicians, specialists (e.g. endocrinologists, nephrologists, cardiologists, etc.), nurse practitioners, physician assistants, diabetes educators, nurses, medical assistants, and pharmacists.

Oral Hypoglycemic Agents (OHA): This term is broadly used to include the wide variety prescription pills used to assist in controlling blood glucose.

Protective mechanisms: The “processes at the individual, family, community or societal levels that buffer or mediate the adverse consequences of threatening risk factors” (Hill, 2007, p. 87).

Resiliency: Resiliency is defined as, “the process of coping with stressors, adversity, change, or opportunity in a manner that enables the identification, fortification, and enhancement of protective factors” (Richardson, 2002, p. 308).

Resiliency research: Resiliency research seeks to identify mechanisms that enhance protection and resiliency within a given population (Billingsley & Morrison-Rodriguez, 2007; Hill, 2007).

Social constructivism: The goal of research from a social constructivist perspective is to trust the participant view of the experience (Creswell & Clark, 2011). There is no one reality; knowledge and reality are created by social relationships and interactions. Therefore, it is important to understand a given phenomena from the perspectives of the individuals who are experiencing the phenomena (Creswell & Clark, 2011).

Social determinants of health: “The circumstances in which people are born, grow up, live, work, and age, as well as systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics” (WHO, 2010).

Type 1 diabetes: Type 1 diabetes is an autoimmune disease that develops quickly and accounts for about 5% of all diabetes (ADA, 2014). The pancreatic beta cell function is destroyed; therefore, the body is unable to produce insulin and the patient requires insulin therapy administered through injections or an insulin pump (ADA, 2014).

Type 2 diabetes: Type 2 diabetes develops gradually and accounts for about 90%-95% of all diagnosed cases of diabetes in adults (ADA, 2014). Type 2 diabetes is progressive and over time the pancreas may gradually lose the ability to produce insulin (ADA, 2014). Known risk factors for Type 2 diabetes include older age, obesity, family history of diabetes, gestational diabetes, sedentary lifestyle, and race/ethnicity (Choi & Shi, 2001). African Americans, Latino Americans, American Indians/Alaskan Natives, and some Asian Americans are at increased risk for Type 2 diabetes (CDC, 2014).

Chapter 2

BACKGROUND AND SIGNIFICANCE

In spite of concerted prevention efforts, Type 2 diabetes remains one of the most common chronic diseases in America and affects approximately 29.1 million people or 9.3% of the general population including 21.0 million who have been diagnosed and another estimated 8.1 million people who are undiagnosed according to the most recent data from the 2009–2012 National Health and Nutrition Examination Survey (NHANES) (CDC, 2014). In order to maintain healthy blood glucose levels, 85.6% of people with diabetes must take prescription medication(s) according to data from the 2010-2012 National Health Interview Survey (NHIS) (CDC, 2014). Nearly half of people with diabetes do not take their prescription diabetes medication(s) as recommended (Aikens & Piette, 2009; Evans, Donnan, & Morris, 2002) and 60% of patients on insulin therapy report missing injections occasionally (Brunton et al., 2011). In a study by Polonsky, Fisher, Guzman, Villa-Caballero and Edelman (2005) 28% of patients with diabetes were unwilling to start insulin therapy; women and minorities were even less willing. Due to the progressive nature of diabetes, some patients will require insulin therapy to obtain optimal glycemic control. As proper medication is necessary for most people with diabetes to maintain consistent, healthy blood glucose, the risk of complications from uncontrolled diabetes significantly increases if patients are non-adherent to prescription medications.

Social Determinants of Health

Social determinants of health include “the circumstances in which people are born, grow up, live, work, and age, as well as systems put in place to deal with illness. These circumstances are influenced by a broader set of forces: economics, social policies, and politics” (WHO, 2010). Diverse ethnic groups suffer from diabetes at much higher rates than non-Hispanic whites (Figure 1).

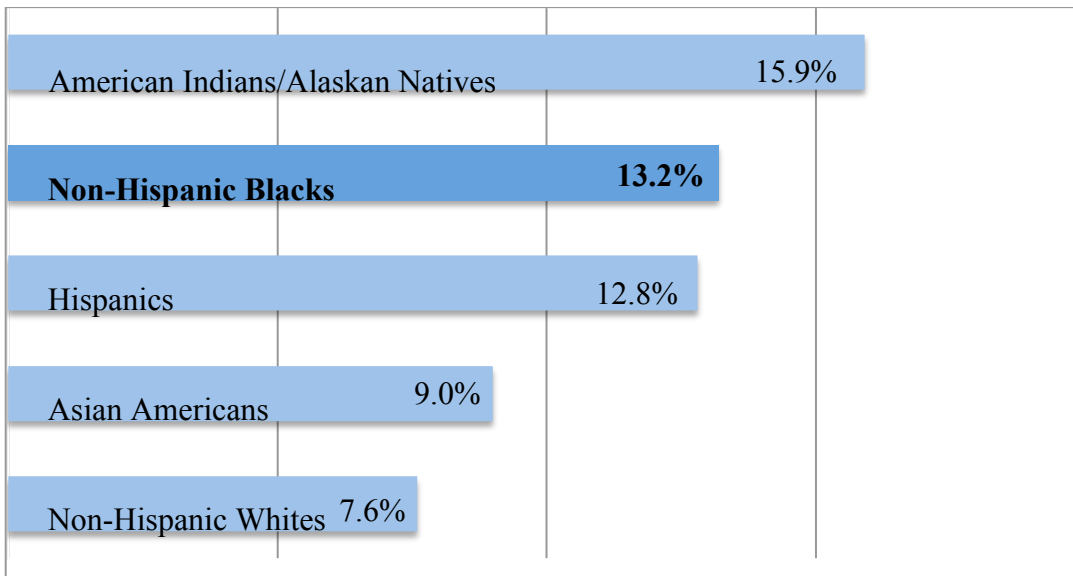


Figure X. Age-adjusted Percentage of People aged ≥ 20 Years with Diagnosed Diabetes, by Race/Ethnicity in the U.S., 2010-2012
Source: 2010-2012 National Health Interview Survey and 2012 Indian Health Service’s Patient Information Reporting System.

Using National Health Interview Survey (NHIS) data from 2010-2012, the CDC (2014) reported rates of diagnosed diabetes in non-Hispanic whites (7.6%) were lower than for non-Hispanic blacks (13.2%) and other racial groups. Moreover, men (13.6%) suffer from diabetes at higher rates than women (11.2 %) and older Americans are at higher risk for diabetes as 11.2 million (25.9%) of those who have been diagnosed with diabetes are 65 years and older (CDC, 2014; NHIS, 2009-2012).

In Arizona, the rate of diabetes has steadily increased from 6.4% in 2002 to 9.1% in 2010 (Figure 2) (Bass & Porter, 2011). Prevalence of diabetes in Arizona varies by ethnicity and race with non-Hispanic whites (8%) having the lowest rate, while 16.2% of African Americans have diagnosed diabetes (Bass & Porter, 2011).

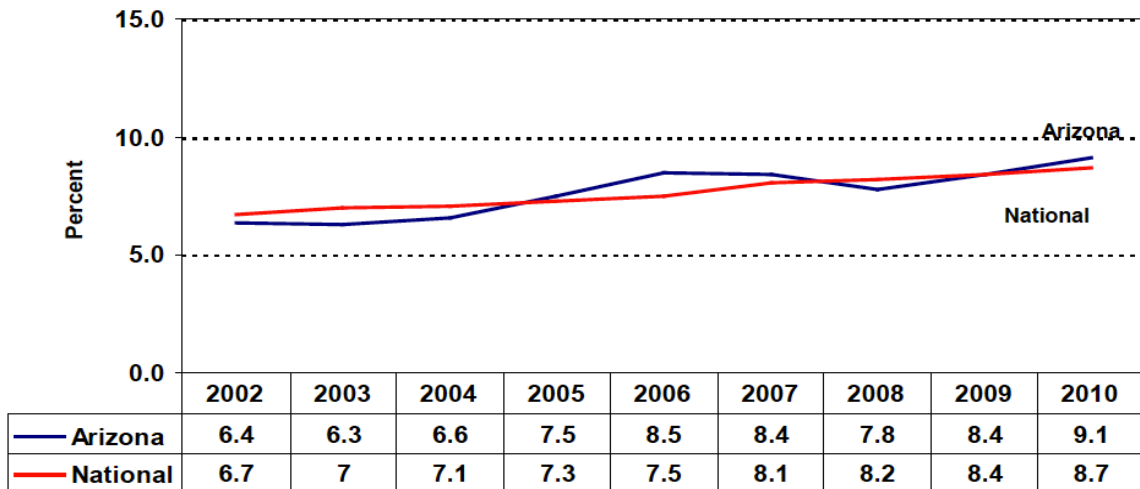


Figure 2. Percentage of Arizona and National BRFSS respondents who reported that they were told they have diabetes in 2002-2010 (Bass & Porter, 2011)

In addition, when the percentage of Arizona adults diagnosed with diabetes is broken out by age categories, dramatic differences can be seen as older adults are being diagnosed with diabetes at much higher rates in recent years (Figure 3).

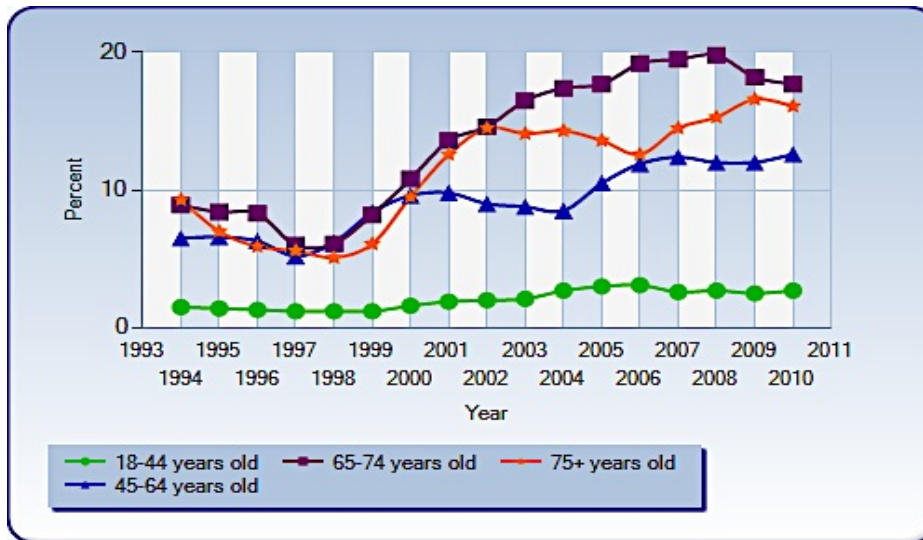


Figure 3. Arizona - Percentage of Adults with Diagnosed Diabetes by Age, 1994 – 2010

Source: Center for Disease Control and Prevention (CDC) Behavioral Risk Factor Surveillance System (BRFSS)

The importance of the effects of societal determinants of health and their influence on the occurrence of diabetes among the poor and excluded in America cannot be stressed enough. While lifestyle behaviors including inactivity, and poor diet along with obesity are associated with increased incidence of diabetes and increased risk for complications, the underlying causes for these lifestyle behaviors have not been adequately understood. Raphael et al. (2003) suggest simply identifying unhealthy behaviors is insufficient; an investigation of social determinants needs to be included in interventions aimed at changing unhealthy behaviors to prevent and manage diabetes in underserved and at-risk populations.

Socioeconomic status (SES) is often measured via education and income (e.g., percent of poverty level). At the most basic level, education is associated with knowledge acquisition, economic potential and cognitive ability; income determines

financial resources. Evans and Kim (2010) suggest exposure to both environmental factors and psychosocial risks (e.g., adverse interpersonal relationships, disordered neighborhoods) explain some of the negative health outcomes for individuals with low SES. Link, Phelan, Miech and Westin (2008) have described SES and its association with health outcomes as “fundamental causes” of disease and mortality. Because they have access to money, resources, knowledge, prestige, and social networks, individuals with higher SES are more likely to have access to new medical technologies and methods of health care than individuals with lower SES (Barr, 2008; Link et al., 2008). Thus, disparities in health outcomes become evident.

The relationship between SES and mortality is more apparent in the case of highly preventable conditions, such as Type 2 diabetes, than in conditions, such as multiple sclerosis and certain types of cancer, with low preventability. The Barker hypothesis, posited by Barker (1995), suggests that the potential for poor health outcomes begins in the womb with inadequate prenatal and early life nutrition having the potential to predispose an individual to the development of Type 2 diabetes in later life. In addition, persistent low social status contributes to this risk in both psychosocial and physiological ways (Barr, 2008; Marmot & Wilkinson, 2003; Mechanic, 2007).

Although the association between income and health is strongest at the lowest income levels, the effects of income persist even above the poverty level (Backlund, Sorlie, & Johnson, 1999; Barr, 2008). In America, rates of diabetes increase as the poverty to income ratio (PIR) decreases (Beckles, Zhu, & Moonesinghe, 2011). The incidence rate of diagnosed diabetes among the poor (11.7%) PIR category and the incidence rate in the high income PIR category (5.5%) were more than double (Figure 4).

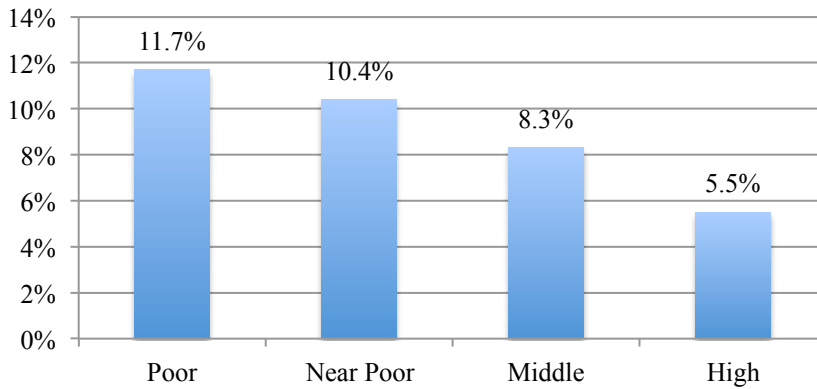


Figure 4. Poverty to Income Ratio (PIR) and Rates of Diabetes in the U.S.

Consistent with national data, Arizona’s rates of diabetes are closely associated with income (Figure 5); those at the lowest income level (< \$10,000) are four times more likely to have diabetes as compared to those who earn \$75,000 or more (Bass & Porter, 2011). It is clear that the very poor in Arizona suffer disproportionately from diabetes.

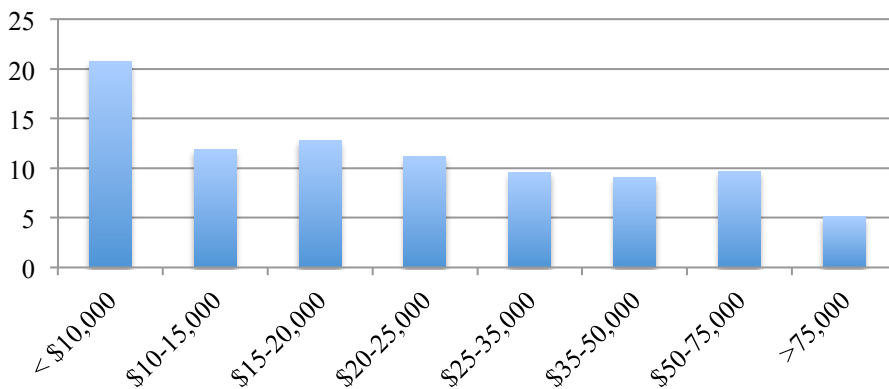


Figure 5. Income Level and Rates of Diabetes in Arizona

Higher education has long been accepted as a stronger individual predictor of good health than either employment or income alone, as it influences both employment and income (Mechanic, 2007; Winkleby, Jatulis, Frank, & Fortmann, 1992). Even when individuals have achieved comparable income levels, more highly-educated individuals tend to experience less hardship due to enhanced cognitive capacity, access to

information, empowerment, and coping skills, all of which enable them to more readily recognize symptoms of health problems, to seek information about treatment, and to more effectively moderate stress, including health-related stress (Barr, 2008; Gottfredson, 2004; Mechanic, 2007; Ross & Wu, 1995). In America, the threshold at which educational differences are substantial is the completion of high school and beyond (Mechanic, 2007). Rates for Type 2 diabetes in America vary considerably according to educational status (Figure 6). In fact, rates of diabetes are nearly double for those who have not completed high school (11.8%) as compared to those who have obtained education beyond high school (6.2%) (Beckles et al., 2011).

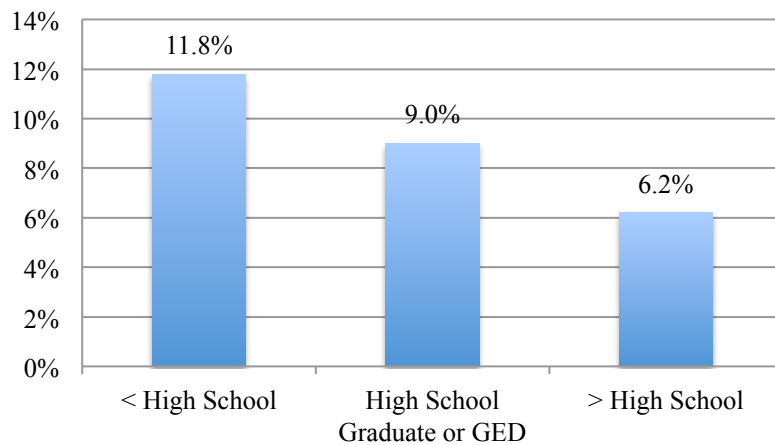


Figure 6. Education Level and Rates of Diabetes in the U.S.

In Arizona, rates of diabetes have a linear relationship with education level (Figure 7). Arizona adults who did not complete high school (17%) are nearly three times more likely to suffer from diabetes compared to those who earned a college degree (5.7%) (Bass & Porter, 2011).

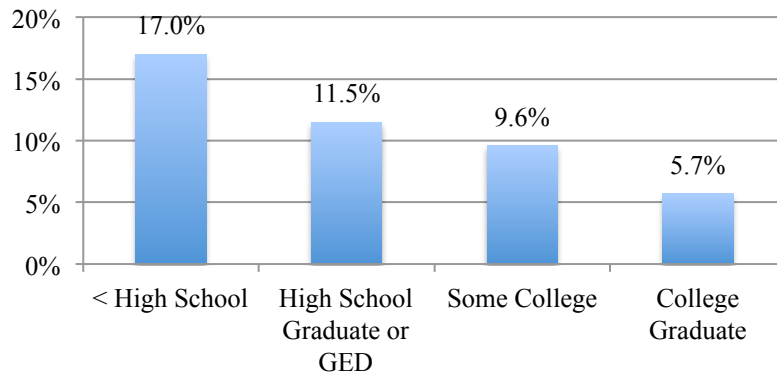


Figure 7. Education Level and Rates of Diabetes in Arizona

Moreover, urban versus rural residency is an important social determinant of health. Bennett, Olatosi, and Probst (2008) combined data from three sources to compare residents in American rural and urban areas. Residents in rural areas were more likely to report fair or poor overall health than those in urban areas (19.5% compared to 15.6%) (Bennett et al., 2008). Furthermore, higher incidence of Type 2 diabetes was found in rural residents (9.6%) as compared to urban residents (8.4%); rates of diabetes were highest for rural American Indians (15.2%) and non-Hispanic blacks (15.1%) (Bennett et al., 2008).

While SES factors and health insurance do account for much of the disparity in health for African Americans, it does not explain all of the difference. Barr (2008) reports that even when accounting for SES and health insurance differences, Blacks are still burdened with higher rates of many chronic illnesses, including diabetes. Some of these differences can be attributed to “neighborhood effects” of decreased social capital linked with residential segregation (Barr, 2008). The accumulated stress of living in an unsafe neighborhood where people do not trust their neighbors, do not feel safe walking outside,

and live in a generally chaotic environment negatively contributes to physiological and mental state, which can have a negative affect on health (Barr, 2008).

Furthermore, some disparities in health outcomes can be traced to racial variation in access to quality medical care (Barr, 2008). This is independent of health insurance and its relationship to access to health care; not all health care is created equal. Clinics available to those who live in impoverished areas may provide very basic services that are inadequate in ensuring optimal resources for treatment of chronic illness.

Luftey and Freese (2005) asserted, “social processes influence people’s health in ways that cannot be identified and contained in medical interventions”; therefore, researchers sought to identify “mechanisms for linking SES and health” (p. 1328).

Luftey and Freese (2005) conducted an ethnographic study of two diabetes clinics that varied substantially on SES and ethnicity. *Park Clinic* was the diabetes clinic with patients from higher SES backgrounds (mean income of \$56,000), few Black patients (12%), and higher education levels (89% with more than a high school education). In stark contrast, *County Clinic* patients had lower SES (mean income of \$12,000), nearly half of the patients were Black (45%), and 36% did not complete high school.

A salient difference between the clinics was that Park Clinic offered a higher level of continuity of care, which means the same physician saw patients over a long period of time (Luftey & Freese, 2005). This allowed for an open, trusting physician-patient relationship to be built over time; healthcare providers got to know their patients and their subsequent needs. County Clinic utilized medical residents on four-week rotations who

were responsible for 75% of face-to-face care. This made it impossible, for patients to develop a strong relationship with one primary healthcare provider (Luftey & Freese, 2005).

Moreover, Luftey and Freese (2005) reported substantial differences in educational resources available at each diabetes clinic. Park Clinic employed several diabetes educators in their on-site diabetes education center who were available for consultation immediately following medical exams. County Clinic did not have this type of on-site resource; instead there was one volunteer diabetes educator available for scheduled appointments one day a week.

Furthermore, more than 40% of County Clinic patients did not have health insurance, which meant they were burdened with additional paperwork before being treated or obtaining necessary medication at the clinic (Luftey & Freese, 2005). Even though financial counselors were available to assist with paperwork, many patients did not use this service and were subsequently not receiving benefits to which they were entitled. Moreover, Luftey and Freese (2005) concluded that many patients “failed to take prescribed medication as a result” (p. 1349). Luftey and Freese (2005) demonstrated that the type of health-related services provided to patients with diabetes are important in evaluating access and quality of care for patients.

Management of Diabetes

At the present time, there is no cure for diabetes; therefore, maintaining healthy blood glucose levels through proper self-management is crucial for avoiding serious complications. Prescribing medication to treat diabetes varies for individuals. Some adults manage diabetes by taking only insulin (12%), while others benefit from both

insulin and oral medication(s) (14%), and the majority requires only oral medication(s) (58%) (CDC, 2014; NHIS, 2007–2009). Approximately 16% of people with diabetes do not take any prescription medication, as they are able to adequately manage diabetes with lifestyle changes including a healthy diet and regular activity (CDC, 2014; NHIS, 2007–2009). Furthermore, diabetes is a progressive illness and increases in medication dosage and types are typically required during the disease process.

Adhering to medical recommendations can present challenges for even the most engaged patients. Effectively controlling blood glucose is complex and requires patients to be engaged daily in their self-care; there is no vacation from diabetes management. While people with diabetes may see their physician often for tests and medication management, the burden of diabetes management rests upon the patient. The patient is responsible for lifestyle changes such as regular exercise, eating healthy foods, daily blood sugar testing, and medication management.

Complications from Uncontrolled Diabetes

Uncontrolled diabetes is the seventh leading cause of death in the United States and can lower life expectancy by as much as 15 years (Xu et al., 2010). In 2007, diabetes was listed as the underlying cause on 71,382 death certificates; poorly controlled diabetes was a contributing factor on an additional 160,022 death certificates for a total of 231,404 deaths (Xu et al., 2010). Overall, Xu et al. (2010) estimate the risk of death for people with diabetes is about twice that of people of comparable age who do not have diabetes.

Complications related to poorly controlled diabetes are generally categorized into microvascular complications or macrovascular complications (ADA, 2012).

Microvascular complications affect small blood vessels, thereby contributing to diseases

of the eyes (retinopathy), the nerves (neuropathy), and the kidneys (nephropathy).

Macrovascular complications affect larger blood vessels and contribute to risk for heart disease and stroke.

In America, poorly controlled diabetes is the leading cause of blindness among adults over 20 years old (Zhang et al., 2010). From 2005 to 2008, nearly 1 in 3 people with diabetes aged 40 years or older had diabetic retinopathy (28.5%) (Zhang et al., 2010). Of those with diabetic retinopathy, 4.4% were so advanced that they were at risk for severe vision loss (Zhang et al., 2010). In 2006, advanced diabetic nerve disease was a major contributory cause of lower-extremity amputations as 60 % of all lower-limb amputations were performed on people with diabetes (Gregg et al., 2014). Uncontrolled diabetes is the leading cause of nephropathy; accounting for 44% of all newly diagnosed kidney failure in 2008 (Gorina & Lentzer, 2008). As of 2008, more than 202,000 people with diabetes-related end-stage renal disease (ESRD) were living on dialysis or with a kidney transplant (Gorina & Lentzer, 2008).

People with poorly controlled diabetes are at increased risk for macrovascular damage, which leads to cardiovascular disease (CVD). In 2004, for those aged 65 and older who died of diabetes-related complications, heart disease was noted on 68% of death certificates and stroke was noted on 16% of death certificates (Gorina & Lentzer, 2008). Furthermore, adults with uncontrolled diabetes die from heart disease at rates two to four times higher than people who do not have diabetes (Gorina & Lentzer, 2008). Moreover, stroke risk is two to four times higher among people with poorly controlled diabetes (Gorina & Lentzer, 2008).

Prevention is the primary strategy for avoiding microvascular and macrovascular complications. Improving glucose control can benefit people with diabetes as every percentage point drop in glycated hemoglobin (A1C), for example, from 9.0% to 8.0%, can significantly reduce the risk of microvascular complications like retinopathy, nephropathy, and other nerve damage by 40% (DCCT, 1993; Stratton et al., 2000). The ADA (2012) defines A1C as a blood test that measures average blood glucose control over the previous two to three months. It is expressed in terms of the percentage of glycated hemoglobin in the blood. In addition to adequate blood sugar control, prevention efforts for people with diabetes must include being proactive in maintaining healthy cholesterol levels and controlling blood pressure.

Complications from uncontrolled diabetes can be reduced or prevented if patients with diabetes take the proper medication(s) to adequately control blood glucose levels (DCCT, 1993). Breitscheidel et al. (2010) report increased health care costs and higher rates of hospitalization are associated with poor medication adherence. Furthermore, when diabetes medications are taken consistently, both microvascular and macrovascular complications are significantly reduced (DCCT, 1993; Gorina & Lentzer, 2008; Stratton et al., 2000). Thus, adherence to a medication regimen is crucial for the health of people with diabetes.

The Conceptualization of Medication Adherence

Trostle (1988) discusses the notion of *compliance* with medical treatment as a concept requiring a dominant medical professional and a dependent patient. He asserts that compliance research was dominated by ideological conceptions of the roles of the physician and the patient in medical care. Furthermore, Trostle (1998) asserts that

negatively labeling clients as “non-compliant” because they follow their own ideas about treatment assumes patients should not have a say in their own care and are disobedient to physician mandates. More recently, Horne et al. (2005) discuss compliance as used in modern medicine, “it betrays a paternalistic attitude towards the patient on the prescriber’s part” and suggest the term compliance should not be used (p. 383).

Horne et al. (2005) assert the concept of “concordance”, which places emphasis on the shared decision-making process between patient and HCP is ideal when making decisions about prescribing treatments. Concordance has an even broader implication as the physician and patient are free to share their views about treatment and move toward the mutual decision about the potential use of medication; in the concordance approach, a decision not to take medication is acceptable (Horne et al., 2005).

After this concordant process, the decision about how to proceed with medical treatment is ideally agreed upon by both parties. Horne et al. (2005) prefer the term adherence to best describe the notion of “sticking to a therapeutic regimen” (p. 383). Cramer (2004) concurs as she defines adherence as “taking medication as prescribed and/or agreed between the patients and the health care provider” (p. 1219). Therefore, the term adherence will be used as a term to describe whether or not the patient has followed the medication plan agreed to by both physician and patient.

Diabetes Medication Adherence

Non-adherence to diabetes medication is associated with an 80% increased risk of death in people with diabetes (Elliot, 2009). Unintentional non-adherence occurs when patients forget to take their medication or take it incorrectly; this accounts for about half of all non-adherence (Elliott, 2009). Conversely, at least half of non-adherence is

intentional. For example, the patient may experience unpleasant side effects or have concerns about long-term effects associated with the medication and make a decision to not take a medication (Elliott, 2009).

Shah et al. (2009) examined rates of filling an initial prescription for diabetes medication in more than 1,000 patients who were primarily Caucasian (95%). The overall first-fill adherence rate for diabetes medication in this sample was 85%; 15% of patients did not receive their initial prescription for diabetes medication. Factors associated with filling their initial prescription were copays less than \$10 and baseline A1C greater than 9%; sex and age had no association.

Kirkman et al. (2015) examined data from more than 200,000 people with diabetes who were prescribed noninsulin medications. Nearly two-thirds (69%) were adherent to their medication. Adherence was associated with older age, being male, social determinants of health (higher education and higher income), lower out of pocket costs, and use of mail order pharmacy. Furthermore, patients who were newly diagnosed with diabetes were significantly less likely to be adherent to diabetes medication (Kirkman et al., 2015).

Rubin (2005) conducted a review of twenty-seven studies, which included a measurement of medication adherence in patients with diabetes. Most studies (25) were only concerned with oral blood glucose lowering medications as opposed to insulin therapy. Adherence to oral hypoglycemic agents (OHA) varied widely from 65% to 85%. Although in some populations, for example, Medicaid recipients (Dailey, Kim, & Lian, 2001) and those taking multiple medications (Melikian, White, Vanderplas, Dezii, & Chang, 2002) even lower rates of adherence were reported at 36% to 54%. Rubin (2005)

reported six factors influencing adherence: (1) comprehension of the medication regimen; (2) perception of benefits; (3) side effects; (4) cost of the medication; (5) complexity of the medication regimen; and (6) emotional well-being of the patient.

Cramer (2004) reviewed fifteen studies that included a measurement of medication adherence and discovered wide variation in rates of adherence (36% to 93%). Cramer (2004) reviewed five studies that used electronic monitoring to track adherence of dosing and found OHA adherence rates of 61% to 85%, which more closely matched the Rubin (2005) review. Brunton et al. (2011) reported broad adherence rates to OHA among patients with Type 2 diabetes to be 36% to 93%, which is consistent with Cramer (2004).

Moreover, medication adherence varies by type of OHA. Shenolikar, Balkrishnan, Camacho, Whitmire, & Anderson (2006b) found adherence for the diabetes medication pioglitazone was lower in African American Medicaid enrollees as compared to white peers; there was a 12% overall lower rate of adherence for African Americans as compared to whites. However, after controlling for demographics (e.g. age, gender), African Americans were not different in adherence rates to pioglitazone as compared to whites (Shenolikar, Balkrishnan, Camacho, Whitmire, & Anderson, 2006a).

Evans et al. (2002) found especially low adherence rates for two commonly used OHAs, metformin and sulphonylureas, for Type 2 diabetes patients only taking oral medication. Half of those who were prescribed metformin were not taking the medication as prescribed. Moreover, Pladevall et al. (2004) found adherence rates for metformin was 57% in a diverse sample of more than 1000 patients, which included 41% African Americans. Non-adherence was significantly associated with poorer glucose control as

evidenced by higher A1C. In addition, more than one-third of those who were prescribed sulphonylureas were non-adherent (Pladevall et al., 2004).

Few studies examined rates of adherence for insulin therapy. Rubin (2005) reviewed two studies that evaluated adherence to insulin therapy in people with Type 2 diabetes and concluded that the adherence rate was 60% to 80%. Cramer (2004) found that younger patients were less adherent to insulin than older patients and filled prescriptions for only about one-third of their prescribed insulin. Brunton et al. (2011) reported adherence to insulin therapy to be 70% and 60% of patients reported missing an occasional injection.

The estimated diabetes costs in the United States for 2012 are \$245 billion; this includes \$176 billion for direct medical costs and another \$69 billion in indirect costs (disability, work loss, premature death) (CDC, 2014). Breitscheidel et al. (2010) reviewed eleven studies of healthcare costs and the relationship with diabetes medication adherence. They concluded that improving overall medical adherence, including prescription adherence, could lead to reductions on the total healthcare costs for Type 2 diabetes. Annual cost savings per patient for the treatment of Type 2 diabetes ranged from \$4,570 to \$17,338. In a review of seven studies, non-adherence to diabetes medication was associated with higher overall healthcare costs. Furthermore, non-adherence to diabetes medications was related to higher hospitalization costs (Breitscheidel et al., 2010; Shenolikar, et al., 2006a).

Lee et al. (2006) conducted another meta-analysis of studies on adherence among people with diabetes to calculate the economic effect. They concluded that improved adherence would result in decreased health care costs of about 8.6% to 28.9%. Most of this decrease in costs would be in lower hospitalization costs of 4.1% to 31%.

Barriers to Medication Adherence

Many patients with diabetes are prescribed multiple medications, including medication for other conditions such as hypertension, hyperlipidemia, or CVD. For patients who were taking OHA and antihypertensive medications, half underused these medications, citing cost as the primary barrier (Aikens & Piette, 2009). In fact, the majority of patients reported the cost of medication or related copays as the primary reason they did not take their diabetes medication as prescribed (Aikens & Piette, 2009; Piette, Heisler, & Wagner, 2004; Rubin, 2005).

Piette et al. (2004) surveyed 660 veterans with chronic illness who reported underusing their prescription medications due to cost. Many patients stated they knew in advance they would not be taking the medication as prescribed, with nearly two-thirds choosing not to discuss with their health care provider their inability to afford the medication (Piette et al., 2004). Of these chronically ill patients who did not talk to their physician about the prohibitive cost of medications, 66% reported that nobody asked them about their capacity to afford the prescribed medication(s) and 58% thought there was nothing their healthcare provider could do about helping them pay for prescription medication (Piette et al., 2004). Rubin (2005) found patients reported a variety of reasons for not discussing medication costs with physicians including the patients did not believe their healthcare providers could help with costs (50%), cost was not important enough to

mention (39%), embarrassment (35%), and patients did not believe there was enough time to discuss costs (30%).

Piette, Beard, Rosland, and McHorney (2011) concluded that addressing patient beliefs about their medication could decrease cost related non-adherence. From survey data of patients with chronic illness from diverse SES backgrounds, Piette et al. (2011) suggest that cost-related non-adherence may be associated with other factors including patient beliefs about medication, which influences the value that a patient places on prescription medication. For example, respondents who reported greater concerns about negative side effects from prescription medication had twice the odds of reporting cost related non-adherence to medication (Piette et al., 2011). In addition, patients who did not believe they really needed their medication were more than twice as likely to report non-adherence due to cost. Furthermore, beliefs about susceptibility to complications and efficacy of prescribed medication were considerations when patients were deciding whether or not to take prescription medication as directed (Piette et al., 2011).

Beyond cost related non-adherence, Rubin and Peyrot (2001) discussed common fears regarding initiating insulin therapy. The first reason many people offered for their resistance to insulin treatment was that injections are painful. While this may be the most readily expressed reason, it may not be the most salient reason for resistance to insulin therapy (Leslie & Satin-Rapaport, 1995).

Many people with diabetes are concerned that taking insulin injections will further restrict and complicate their life, thereby reducing quality of life (Peyrot et al., 2005; Rubin & Peyrot, 2001). Insulin therapy has the potential of making life more complex as it requires carrying insulin, syringes, and a glucose meter

everywhere. Moreover, new skills must be acquired to maintain a healthy balance of insulin and glucose in the body to avoid dangerous extremes.

Some people with diabetes were opposed to insulin therapy because they were concerned that their diabetes, and therefore, their health, was substantially declining (Peyrot et al., 2005; Rubin & Peyrot, 2001). Coupled with this concern were feelings of failure associated with past mismanagement of their diabetes that they believe may have prevented the need for insulin (Peyrot et al., 2005). Perfect management of diabetes is not possible and, as stated earlier, as many as one-half of diabetes patients are non-adherent to their prescription medications (Brunton et al., 2011; Cramer, 2004; Rubin, 2005).

Other fears included unwanted side effects from insulin therapy (Peyrot et al., 2005; Rubin & Peyrot, 2001). For example, weight gain is common with insulin therapy and this becomes particularly distressing for those who have been struggling to lose weight (Rubin & Peyrot, 2001). Moreover, hypoglycemia (insulin reaction or low blood sugar) is more likely when patients are on insulin therapy. Hypoglycemia can be frightening, embarrassing, and even dangerous. Many patients prefer having elevated glucose, even if they recognize it is harmful in the long-term, as opposed to the discomfort of an insulin reaction (Rubin & Peyrot, 2001).

Some people reported resistance toward insulin therapy because they believe that insulin actually causes complications (Rubin & Peyrot, 2001). These people often cited serious complications experienced by relatives or friends shortly after initiating insulin therapy. This is a spurious relationship as insulin therapy is actually related to the

prevention of diabetes-related complications, which has been confirmed in numerous reliable studies (DCCT, 1993; Turner et al., 1998; U.K. Prospective Diabetes Study, 1998).

Some people with diabetes were concerned about negative social pressures, as they believed others would view them differently if they use insulin to control their diabetes (Peyrot et al., 2005; Rubin & Peyrot, 2001). If in the past, family and friends communicated blame and judgment toward the person with diabetes, it would be reasonable to assume initiation of insulin therapy would only increase anxiety, negativity, or judgment from others.

In addition to these fears, many people with diabetes do not have a trusting relationship with their healthcare provider (Peyrot et al., 2005; Rubin & Peyrot, 2001). Polonsky (2005) confirmed that many people with diabetes did not feel physicians had sufficiently provided diabetes education, support, encouragement, or discussion about treatment options. These patients were particularly oppositional, even resentful, toward insulin therapy. In fact, Corbie-Smith, Thomas, & St. George (2002) found that African American patients were significantly more likely than whites to believe their physicians exposed them to unnecessary risks. In addition, African American respondents had a significantly higher overall mistrust for physicians than white respondents (Corbie-Smith et al., 2002).

Medication Adherence in Culturally Diverse Populations

Mann, Ponieman, Leventhal, and Halm (2009) surveyed 151 low-income Latinos (58%) and African Americans (34%) with diabetes. Eighteen percent reported having difficulty taking their diabetes medication, 16% were worried about the possibility of

becoming addicted to their medication, and 12% believed they only had diabetes when they were experiencing elevated blood sugar. More concerning was that nearly half of people with diabetes in this study (49%) believed they had little control over their illness (Mann et al., 2009). All of these beliefs can have a detrimental effect on medication adherence.

In a survey of veterans with bipolar disorder by Zeber et al. (2011) minority patients were less likely to be adherent to their medications to treat bipolar disorder than non-Hispanic whites. Moreover, Zeber (2011) concluded financial barriers were not as influential as other psychosocial barriers. Potentially modifiable risks that were found to have an effect on medication adherence included beliefs about the efficacy of the medication, the patient's relationship with the healthcare provider, substance abuse, degree of social support, and illness perceptions.

In their study of 542 African Americans with Type 2 diabetes, Hill-Briggs et al. (2006) examined the role of problem-solving and self-management behaviors. Medication adherence was measured by the 9-item Moritsky Medication Adherence Scale (Moritsky et al., 1986). The ability to effectively engage in problem solving was significantly associated with greater medication adherence. They concluded that knowing what strategies are successfully used to problem-solve medication barriers may be useful to others who struggle with overcoming barriers to medication adherence.

Medication Adherence and Glycemic Control in African Americans

Hill-Briggs, Gary, Bone, Hill, Levine, and Brancati (2005) examined medication adherence in 181 urban dwelling African Americans with Type 2 diabetes. Almost 75% of participants were adherent with diabetes medications. Older age was associated with

greater adherence and better glycemic control. A1C was significantly lower for those who were adherent in taking diabetes medications as measured by 4-items from the Moritsky Medication Adherence Scale (Moritsky et al., 1986) plus one additional item, “*Do you ever run out of your medication?*” Significant differences in A1C were observed between participants who reported *running out of medication* and *carelessness with taking medication* as compared to those who did not report these behaviors.

Heisler et al. (2007) suggest that understanding mechanisms associated with medication adherence may be a means to addressing barriers to adherence. Heisler, et al. (2007) examined 1034 patients with diabetes to determine racial differences related to disparities in glycemic control. Clinical characteristics included type of antihyperglycemic treatment regimen (no medication, oral medication with daily glucose testing, oral medication without daily glucose testing, and insulin either with or without oral meds). Blacks had significantly worse glycemic control than whites (Heisler, et al., 2007). More Blacks were taking insulin and also reported lower rates of medication adherence (Heisler, et al., 2007); lower A1C was associated with adherence to diabetes medication(s). Furthermore, Blacks also reported more diabetes-related comorbidities (Heisler, et al., 2007). This further demonstrates the need to address the potentially modifiable behavior of medication adherence as a means of improving glycemic control in African Americans.

Social Support and Medication Adherence in African Americans

Chlebowy and Garvin (2006) conducted a study (N=91), which included 27 African Americans living in the southeastern United States to investigate psychosocial variables (social support, self-efficacy, and outcome expectations), the relationship to

self-care behaviors (glucose testing, exercise, diet, and medication taking) and glycemic control. They found a significant relationship between outcome expectations and the total score for self-care behaviors for African Americans and Caucasians. Understanding more about how outcome expectations may affect medication adherence would be valuable.

Chlebowy, Hood, and La Joie (2010) conducted focus groups with 38 African American adults with Type 2 diabetes living in a southeast urban community to determine facilitators and barriers to diabetes self-management. Family support was a facilitator to medication management; some family members provided direct assistance in the administration of medications and/or provided cues that prompted taking medications.

Tang, Brown, Funnell, and Anderson (2008) conducted a study with 89 African Americans with Type 2 diabetes living in Detroit, Michigan and examined social support and its relationship with self-care behaviors (diet, exercise, glucose testing, foot care, and medication use). Medication use was assessed by one question that asked, *On how many of the last 7 days did you take your medication as your physician recommended?*

Negative social support was predictive of greater non-adherence to diabetes medication(s). In other words, some comments from family and friends reminding the person with diabetes to take his or her medication may be perceived as nagging and result in decreased medication adherence. Tang et al. (2008) suggest that because taking medication is often done in solitude, there is less opportunity to receive positive feedback.

Brody, Kogan, Murry, Chen, and Brown (2008) conducted a study of 200 southern, rural dwelling African Americans with Type 2 diabetes and were primarily concerned with social support and the relationship to glucose testing and A1C. Self-

esteem, optimism, and depressive symptoms in both the patient and support person were significantly related to blood sugar control. Brody et al. (2008) did not include any measurement of medication adherence. However, this does suggest that personal psychological characteristics of both the person with diabetes and the support person are important factors in controlling blood sugar.

While the challenges to diabetes medication adherence in the African American population are well documented, little attention has been given to those who have successfully overcome these barriers. For that reason, this study engaged in a shift from non-adherence as viewed through the lens of problem-orientation to adherence as viewed through resiliency with consideration of the eco-systems theoretical framework.

Resiliency Theory and Eco-systems Theory

Resiliency theory provides the lens through which the data can be interpreted and eco-systems theory provides the framework for viewing resiliency at various levels. Thus, resiliency was observed at the individual, family and friends, community (e.g. healthcare providers, co-workers, church relationships), and society levels (e.g. historical context, policies, health insurance). Furthermore, the interview questions were developed with these theoretical perspectives as framework (Appendix C). The questions begin with the individual, family and friends, and broaden to include community and societal influences on resiliency. Moreover, questions were formulated with resiliency perspectives of asset, competence, risk, and adversity identified as aspects of potential resiliency.

The lens of resiliency theory focused on strengths exhibited by African Americans with diabetes who have been adherent to diabetes medication(s). Resiliency is

defined as, “the process of coping with stressors, adversity, change, or opportunity in a manner that results in the identification, fortification, and enhancement of protective factors” (Richardson, 2002, p. 308). Furthermore, resiliency theory allowed for the exploration of internal and external qualities that enable people to go beyond simply rebounding from difficulty, to experiencing insight and growth in the process. This process may include individual traits of resiliency, the disruptive and integrative process of adhering to medication(s) for diabetes, and any other forces that have contributed to growth in individuals. This person in environment, strengths-based approach is useful in uncovering culturally grounded strategies already used in the African American community, which allows for culturally appropriate replication of those strategies for the benefit of others in the community.

For the purposes of this study, culture is defined as “the set of values held by a community and its corresponding worldview” (Marsiglia & Kulis, 2009, p. 4). Hruschka (2009) further asserts, “Culture has inertia and that culture is to some extent shared” (p. 237). Moreover, risk and resilience vary across ecological and cultural contexts; they are related to cultural expectations for normative behavior (Yates & Masten, 2004). Thus, cultural influences and norms as seen through resiliency are important in understanding diabetes medication adherence in the African American community.

Primarily, deficit models have been used to research African American people. This problem-oriented approach has focused on the weaknesses and deficiencies of individuals and groups (Hill, 2007). Recently, the focus has been shifting to examining the strengths of African Americans as an alternative lens referred to as “resiliency research” (Billingsley & Morrison-Rodriguez, 2007, p. 76; Hill, 2007). Yates and Masten

(2004) stress the importance of “promoting competence through positive models of intervention and change, in addition to reducing or ameliorating the effects of adversity” (p. 522). Resiliency research seeks to identify mechanisms that enhance protection and resiliency within a given population (Hill, 2007). Conceptually, members of the African American community have used the mechanisms that are uncovered; therefore, the researcher simply facilitated the power of the community to be able to spread resilient strategies and supports to others who may need them.

Yates and Masten (2004) suggest, when identifying patterns associated with resilience, there is a need to understand the related concepts of competence, adversity, asset, and risk. *Competence* can be conceptualized as the adaptive use of internal and external resources to negotiate challenges in order to achieve positive outcomes (Yates & Masten, 2004). *Adversity* refers to any experience that has the potential to disturb healthy functioning and adaptation (Yates & Masten, 2004). *Assets* are resources within a given population that enhance the potential of positive development and outcomes; while *risks* are those factors and conditions that increase the probability of unhealthy outcomes within a given population (Yates & Masten, 2004).

In research with at-risk youth and young adults, resiliency is proposed as an important mechanism of protection (Billingsley & Morrison-Rodriguez, 2007; Hill, 2007; Rutter, 1987). Rutter (1987) conceptualized resiliency as adaptive or healthy responses to stressful circumstances. A concise definition of resilience is, “the ability of individuals or families to respond adaptively to factors that are likely to increase stress or negative

outcomes” (Hill, 2007, p. 87). Therefore, resilience can be enhanced when responding to difficult situations and circumstances. Hill (2007) proposes the four protective mechanisms consistent with resilience as follows:

- (1) The reduction of risk impact, including processes that alter the risk, or the person’s response to risk;
- (2) The reduction of negative chain reactions that follow exposure to the threatening effect and contribute to long-term effects of exposure;
- (3) Enhancing self-esteem and self-efficacy, developed through personal relationships, new experiences and task accomplishment;
- (4) Opening up of opportunities or processes that permit the individual to gain access to resources or to complete important transitions. (pp. 76-77)

The resiliency conceptual framework can be used to identify protective mechanisms that may enhance resiliency in African Americans with diabetes. Protective mechanisms are defined as, “processes at the individual, family, community or societal levels that buffer or mediate the adverse consequences of threatening risk factors” (Hill, 2007, p. 87). Moreover, Rutter and Sroufe (2000) suggest, “mechanisms involved in causation might entail dynamic processes operating over time, that indirect chain effects might often be present, and that there might be several different routes to the same outcome” (p. 268).

Process-oriented resilience models are powerful because they go beyond the static trait model, which simply identifies individual characteristics of resiliency without examining the process of how those traits were acquired or how those traits create resiliency in people. In addition, a clearer understanding of the causal processes in resilient adaptation can be used to create effective practice interventions and policies (Miles & Huberman, 1994; Yates & Masten, 2004).

This resiliency framework distinguishes protective mechanisms at several ecological levels including individual, family, community, and society (Figure 8). At the individual level, the focus is on uncovering the processes associated with internalizing positive regard for self, increasing self-efficacy, and promoting internal locus of control (Hill, 2007). At the family level, processes that increase support, foster healthy social interaction, and strategies that actively encourage and assist African Americans with diabetes will be uncovered (Hill, 2007). At the broader community level, the focus is on identifying the role of mediating structures, both formal and informal (e.g. church, workplace, friendships, healthcare team, neighborhood). Mediating structures can be defined as, “informal or formal groups at the family or community levels that offset or buffer the adverse consequences of threatening risk factors” (Hill, 2007, p. 87). The society level includes historical influences and socioeconomic differences (Walters, 2002).

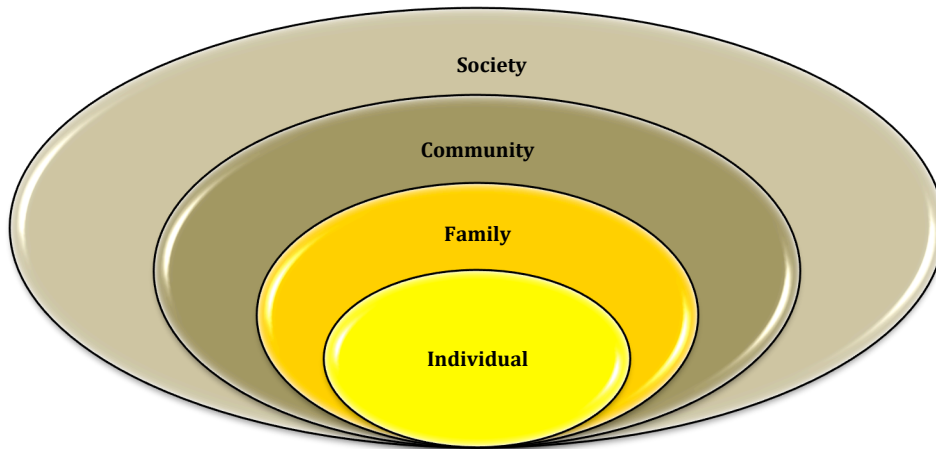


Figure 8. Ecological Systems Framework

Individual Characteristics of Resiliency

Some common characteristics identified in resilient African Americans include the positive values of personal responsibility, respect for others, and high self-esteem (Billingsley, 1999; Hill, 2007). In addition, resilient people often have a strong religious orientation as expressed by a deep sense of spirituality (Billingsley, 1999; Gallup, 1995). People who have a strong internal locus of control are more likely to effectively manage diabetes than those whose locus of control is primarily external (Ajzen, 2002). Furthermore, Hill (2007) suggests that young people who exhibit strong peer resistance are more resilient. This need to resist peer pressure does not stop when a person becomes an adult and may be a necessary skill for effectively managing diabetes and taking prescription medication. These individual characteristics in conjunction with reciprocity or the notion of mutual support contribute to resiliency in African Americans (Boyd-Franklin, 2003).

Resilience in Families

Resilient people are able to exhibit strong social competency in multiple settings throughout their lives (Hill, 2007). A primary protective mechanism for resilience is effective communication patterns within the family, which transfers to other relationships and extends to community interactions (Hill, 2007).

In addition, ethnic pride, especially as it relates to biculturalism, is associated with resilience. Adults who maintain strong identification with their African American roots and have the ability to navigate the dominant culture have higher levels of social competence than their peers who do not have a dual cultural orientation or biculturalism (Boyd-Franklin, 2003; La Fromboise, Coleman, & Gerton, 1993).

African Americans have flexibility in their roles within the family, which may have the effect of increasing social support (Boyd-Franklin, 2003; Hill, 2007). Furthermore, Hill (2007) suggests that Black couples tend to be more willing to share household duties than white couples. In addition, this flexibility in roles expands the types of support that may be available to African Americans with diabetes as family members may be more willing to take on extra responsibilities in order to ease the burden of another family member.

African Americans have a higher proportion of multigenerational households with about 12% of African American children living in the same household as their grandparent(s) and in some regions of America, from 30% to 70% of African American children live with grandparents (National Policy and Resource Center on Women and Aging, 1996). How this living arrangement may affect health and self-management of diabetes is unclear. Can the responsibilities of caring for grandchildren and living within a multigenerational family affect social supports in some meaningful ways?

Community and Societal Protective Mechanisms

Hill (2007) suggests that formal and informal groups may serve to decrease burden for African American people and families when stressful events occur. Boyd-Franklin (2003) identified strengths found in kinship networks, relatives that are in close proximity, but not living in the same household. Kinship networks may provide a variety of social and economic resources including care for the elderly and disabled, food, financial supports, healthcare, and transportation (Hill, 2007).

Positive peer influences are a valuable protective mechanism for providing enhancement of resiliency and social competence for some African Americans

(Hill, 2007). Strong ties with neighbors and friends may allow the transmission of health related information, encouragement, and practical supports. In addition to informal groups, memberships in formal groups, which include neighborhood groups, community centers, churches, health clinics, mental health agencies, and organizations that serve elderly populations may be important resources for those who have a chronic illness.

The Black church has long been a source of strength for African Americans. Billingsley and Morrison-Rodriguez (2007) create a picture of the Black church as a social institution that has the power to touch all aspects of African American life. In fact, Dr. C. Eric London describes the Black church as follows:

Beyond its purely religious function, as critical as that has been, the Black church in its historical role as lyceum, conservatory, forum, social service center, political academy, and financial institution, has been and is, for Black America, the mother of our culture, the champion of our freedom, the hallmark of our civilization. (Lincoln, 1986, p. 3)

Billingsley and Morrison-Rodriguez (2007) further assert during times of difficulty, “African American people will turn to the church for guidance, support, and leadership” (p. 65).

Using general systems theory as a conceptual framework, Billingsley and Morrison-Rodriguez (2007) examined the interaction of the Black family with the Black church. Billingsley and Morrison-Rodriguez (2007) suggest that grandmothers form the membership base for most Black churches and may be more likely to receive assistance and support from the church than other individuals. Historically, the Black church has provided social and economic resources to individuals throughout their life course, which extends to the elderly and disabled (Hill, 2007).

Billingsley and Morrison-Rodriguez (2007) suggest the Black church is in a position to be an “agent of change for protecting the most vulnerable African American families” and have a profound influence on the future direction of the Black family (p. 58). It is important for social workers and health care providers to understand the complexity of African American social systems and how those systems function in order to work in a culturally congruent way to improve health outcomes and quality of life for African Americans.

Moreover, large Black churches may have health ministries that allow congregants to obtain health information from trusted sources. Health ministries build upon the strengths of the African American community by promoting health and wellness with a focus on body, mind, and soul (Warren & Charles, 2011). Often, members of the Black Nurses Association (BNA) are utilized to assist with the church health ministry. The BNA is a non-profit organization that address the health needs of the African American community through education and participation in health fairs and provision of information on health-related issues in the local area as well as throughout the state (Black Nurses Association of the Greater Phoenix Area, 2013).

Historical Context

In addition to community influences of resilience, the historical context for African Americans must be considered. African Americans have a unique history of institutional slavery and domination by colonialism (Mann, 2001). Social, political, and economic struggles have persisted and continue to affect African Americans in modern times (Walters, 2002). Furthermore, Foreman (1999) suggests that a competition exists between those Blacks who are educated middle and upper SES and those who are of a

lower SES. The power differential between these groups of African Americans certainly contributes to their resilience and must be considered as part of the ecological system in which the individuals are nested.

African Americans have a history of oppression that continues today. Regarding the health care of slaves, Collins (1853) states,

The slave also knows, that if he is sick, he will be properly attended to, that he may the sooner recover, and resume his duties; that if his children are sick, they too will be taken care of, for the money they are soon to be worth. (p.15)

The health of the plantation owner's workforce was imperative to his economic success; therefore, it profited him to take care of his workers (Andreae, 2009; Collins, 1853).

However, the manner of care was usually dictated by the plantation owner and depended upon the resources available and the perceived worth of the sick slave (Haller, 1972).

Larger plantations were more likely to bring in professional medical care, but many owners did not consult physicians when Blacks were ill (Haller, 1972). For the most part, slaves were at the mercy of their owner to determine what type of medical care would be obtained. Principally, the plantation owner, his mistress, or the overseer, became the physician (Andreae, 2009; Haller, 1972).

Sellers (1994) states, "A slave who became ill meant loss of working time; death, an even greater loss" (p. 109). For slaves, a great deal of the health care was provided by folk healers, grandmother midwives, lay nurses, and through other social networks such as churches (McBride, 2005). Furthermore, grandmothers were an integral, respected part of the health care system; they provided a devotion to their patients that was unparalleled in the broader community (McBride, 2005). White (1983) suggests that older women who provided midwifery were dubbed "doctor women" (p. 252) and were known to have

a complex understanding about the proper use of herbs for curing sickness. In treating sickness, healers became an instrument of a higher power and exercised control that was equally empowering for the healer and the patient (Andreae, 2009).

Even so, slaves were often reluctant to report illness to the overseer; they feared being accused of malingering (Andreae, 2009). Some slaves complained of sickness to avoid work, which contributed to stereotyping slaves as lazy or deceptive (Andreae, 2009). Therefore, the revealing of sickness created a dilemma for the slave and overseer; genuine sickness needed to be treated to avoid loss of work time or death, but allowing a slave to convalesce, resulted in a reduction of the labor force (Andreae, 2009). In either case, profits would suffer.

This historical view of the treatment of the sick may continue to influence African American notions about the proper care of disease in contemporary times. The inertia inherent in culture and the inevitable sharing of cultural orientations may persist (Hruschka, 2009). How African Americans view sickness and the steps they take to engage in treatment may echo back to these early years in America. There may be a lingering perception of suspicion regarding whether someone is truly sick and the person who is ill may be perceived to be less valuable than his or her healthy counterparts.

Historic Gender Roles for African Americans

Slavery schooled Black women in self-reliance and self-sufficiency; together they firmly resisted domination of masculine authority. Some believe this has contributed to the modern day matriarchal Black family. Enslaved women often relied upon the skills of slave midwives to assist with birthing; this interdependence permeated other areas of their lives, as women depended upon one another for help in raising children and worked

together to accomplish tasks (White, 1983, p. 255). Once a female slave had a child, a variety of privileges were bestowed upon her.

Moreover, the practice of “abroad marriages”, spouses living on different plantations, may have intensified female independence and the maternal role, as spouses were only able to see one another once or twice a week (White, 1983, p. 255). This concept of *matrifocality*, which emphasizes “the fact that women *in their role as mothers* are the focus of the familial relationships” (White, 1983, p. 256) was central to the Black slave family suggesting an inevitable hierarchy of the mother-child relationship over the husband-wife relationship. When matrifocality exists, the role of the father is secondary to the role of the mother when considering survival of the family unit (White, 1983). In summary, female interdependence and cooperation reduced the owner’s leverage over African American slaves, which necessitated female self-reliance, encouraged the mother-child bond as more sacred than the husband-wife relationship and enabled Black families to survive slavery.

White (1983) suggests that while African American men and women share a common culture, they likely view their role as distinctly different within that shared culture. For example, in a society where women form their own groups and associations, the women’s roles may complement the men’s, but women exist in an independent environment. In addition, contemporary African American women continue a matrifocality and see their priority as caretaker of children and other family members.

Summary of Theoretical Frameworks

This study sought to understand the strategies and processes associated with adherence to diabetes medication(s), including insulin, for African Americans. Using

resiliency theory as a lens enabled the exploration of a variety of potential mechanisms that may contribute to diabetes management, especially medication adherence, in African Americans with Type 2 diabetes. Moreover, the eco-systems conceptual framework created a structure for investigating protective mechanisms within the individual, the family, the community, and the society (Hill, 2007). When identifying patterns associated with resilience, the concepts of competence, adversity, asset, and risk (Yates & Masten, 2004) directed the formation of questions that guided discussion in both the focus groups and individual interviews. Moreover, the four protective mechanisms associated with resilience proposed by Hill (2007) were used as a conceptual framework for creating questions to elicit resilient strategies and processes. These protective mechanisms are:

- (1) The reduction of risk impact, including processes that alter the risk, or the person's response to risk;
- (2) The reduction of negative chain reactions that follow exposure to the threatening effect and contribute to long-term effects of exposure;
- (3) Enhancing self-esteem and self-efficacy, developed through personal relationships, new experiences and task accomplishment;
- (4) Opening up of opportunities or processes that permit the individual to gain access to resources or to complete important transitions. (pp. 76-77)

Moreover, resiliency theory provides a unique lens through which to view the data collected. Uncovering resilient strategies, supports, and processes was the focus of the analysis.

Purpose of this Study

Social determinants of health have been well established and explain much about poor health outcomes (Barr, 2008; Marmot & Wilkinson, 2003). Moreover, access to health care and the physician-patient relationship contribute to obtaining quality health care and necessary medication(s) (Barr, 2008; Luftey & Freese, 2005). However, we

know relatively little about cultural factors that are related to medication adherence. Improving adherence to diabetes medication(s) has the potential to reduce the prevalence of complications associated with poor glucose control in people with diabetes (DCCT, 1993) and reduce the cost of health care (Breitscheidel et al., 2010; Shenolikar et al., 2006a).

Moreover, much is known about reasons for non-adherence to diabetes medications (Piette et al., 2011; Rubin, 2005) and psychological insulin resistance (Peyrot, et al., 2005; Polonsky et al., 2005); however, little is known about those who have managed to overcome the barriers to medication adherence. By uncovering the mechanisms used by African Americans with diabetes related to diabetes medication(s) adherence, mechanisms may be better understood and strategies to increase medication adherence could be extended to those African Americans who are struggling. As the strategies will come from within the African American community, cultural congruence is assured.

Furthermore, public health implications for uncovering mechanisms related to diabetes medication adherence have the potential to influence health messages and enhance effective communication with African American people with diabetes who need medication in order to avoid consequences related to poorly controlled blood sugar. Creating positive messages for medication adherence based upon the strengths present in the African American community has the potential to reduce the rate of complications due to poor glucose management in this population.

This study is guided by the broad question, “What mechanisms are associated with adherence to diabetes medication(s), including insulin, for African Americans?”

This research project has two primary aims:

Aim 1: To examine what individual and broader environmental mechanisms are associated with adherence to diabetes medication(s) for adult African Americans with Type 2 diabetes.

Aim 2: To identify internal and external factors that enable African Americans with diabetes to go beyond adherence and to develop a broader understanding of the disease and how to manage it.

Previous studies have focused on understanding the scope of non-adherence (Brunton et al., 2011, Cramer, 2004; Rubin, 2005) and reasons for non-adherence (Aikens & Piette, 2009; Piette et al., 2004; Rubin, 2005). The intellectual merit of this study is in developing new knowledge about those who take diabetes medication(s) as prescribed.

Chapter 3

METHODOLOGY

This qualitative study explored the question, “What mechanisms are associated with adherence to diabetes medication(s), including insulin, for African Americans?” By focusing on the resilient strategies, supports, and processes employed by African Americans with diabetes in regard to medication adherence, the researcher aimed to identify culturally compatible strategies and supports for diabetes medication adherence that may be extended to others who struggle to take diabetes medication consistently.

Many studies have identified barriers to medication adherence in general and in diverse populations. Building upon that foundation, this study identified how some African Americans with diabetes have successfully overcome those barriers.

Research Design

This exploratory qualitative study conducted four recorded, gendered focus groups; two groups had approximately two to five men and two groups had approximately two to five women to determine strategies and processes that are used by men, women, and both genders. Berg (2009) suggests at least two homogenous focus groups are necessary for a rigorous study. The researcher and, when available, an African American co-facilitator facilitated focus groups.

After analyzing data using content analysis through the theoretical perspective of resiliency, in-depth individual interviews were conducted; nine women and eight men were recruited for the individual interviews. Stratification will be based on social determinants of health to ensure varied representation. Interviews were conducted where the participant was the most comfortable (e.g., church, community center, library, etc.).

Furthermore, collection of data ceased when “saturation” was reached; Strauss and Corbin (1998) propose that saturation is a “matter of degree” and there is always a potential for new ideas to emerge from qualitative sources. However, as a matter of practicality and best use of resources, through the iterative process of transcription, coding, and analysis, no new themes were emerging from the data. This study had twenty-three participants, which is consistent with Creswell’s (1998) proposition of a range of five to twenty-five participants and Bertaux (1981) suggest a minimum of fifteen participants for a qualitative study.

Recruitment of Participants

African Americans are historically difficult to recruit for research studies; methods of recruitment that appeal to white participants are not necessarily effective for recruitment of Blacks (Ballard, Nash, Raiford, & Harrell, 1993; Yancey, Ortega, & Kumanyika, 2006). Many cite the lack of knowledge about research, mistrust of researchers, fear of being exploited, and the abhorrent practices in the Tuskegee Syphilis Study as significant barriers to participation (Freimuth, Quinn, Thomas, Cole, Zook & Duncan, 2001; Yancey et al., 2006). The Tuskegee Syphilis Study, which intentionally chose not to treat syphilis in African American males from 1932-1972, was the longest therapeutic clinical study in history and has been pivotal to provide impetus for increasing human subjects protections in research. African Americans are most likely to cite the Tuskegee study as the research event that creates suspicion about researchers’ intentions and creates mistrust of the entire process (El-Sadr & Capps, 1992; Freimuth et al., 2001).

Overcoming these understandable barriers to participation requires time on the part of the researchers who must answer questions, build trust, and acknowledge the atrocities of the past research with people of color (El-Sadr & Capps, 1992; Freimuth et al., 2001; Yancey et al., 2006). Even though this study is not clinical research, recruitment was challenging; potential participants may not understand the difference between social science research and other studies placing all researchers under suspicion. Face to face meetings with gatekeepers (e.g. ministers, BNA administrators, housing directors) was vital to building trust and having access to participants who meet the inclusion criteria. It was imperative to clearly explain the study and how others may benefit from the participants' experiences. Potential participants needed to understand their rights and the researcher was committed to taking adequate time to clearly explain informed consent. In fact, after participants reviewed the Informed Consent, the researcher reviewed the highlights with participants to ensure understanding of their rights.

Horowitz, Brenner, Lachapelle, Amara, and Arniella (2009) suggest one of the strongest strategies for recruiting more people of color for research studies is the partnership of academic personnel with the community. Therefore, the researcher spent a great deal of time working through community-based organizations such as churches, the Black Nurses Association (BNA), and other African American organizations concerned with health. Furthermore, the researcher intentionally participated in events hosted by the African American community (e.g. health fairs, lectures, celebrations, women's expos).

Moreover, the researcher made appointments with African American leaders to answer questions about the research study and obtain "buy in". These leaders included

pastors, respected medical professionals, directors of predominantly Black senior housing residences, Black media personnel, and others within the business community. It was important to meet the leaders where they were comfortable and allow them to set the agenda with freedom to ask whatever questions they wanted and share their concerns openly. In a phone call with a prominent African American leader, the researcher revealed that she is white and the leader declared, “I don’t care what color you are! If you want to help us, you’re all right with me.”

Openness and transparency were instrumental to building trust and credibility. As appropriate, the researcher provided written materials including those concerning the research center and those specific to the study including screening questions, focus group and interview questions, flyers, and a 2-page summary of the study. Moreover, leaders were offered electronic copies of all materials to forward to others in the community. The researcher was especially encouraged whenever she was at an event where community members approached her to ask about the progress of the study.

Once entrance into the community was granted, attending a variety of events and building rapport with individuals before introducing the study was paramount. Often, the researcher attended an event, such as a health fair, and provided diabetes-related information, which could lead to a discussion about the study. It was not uncommon to interact numerous times with a person before the individual disclosed he or she had diabetes.

Theoretical Perspectives in Data Collection

From the social constructivist worldview, the goal of research is to seek to understand the participant view of the phenomena (Creswell & Clark, 2011) In this

particular study, the researcher sought to collect and analyze the shared cultural experiences of African Americans with diabetes. Creswell and Clark (2011) suggest social constructivism is a result of co-creating the subjective meaning, both socially and historically. Therefore, the data was analyzed and description was provided from the African American perspective (Creswell & Clark, 2011). To facilitate this process, probing questions assisted in constructing shared definitions by the community concerning responses to semi-structured questions. Moreover, African American community partners vetted the questions and asked to provide further illumination of cultural interpretations to increase understanding of concepts expressed by participants.

The researcher used the lens of resiliency theory to uncover mechanisms that lead to adherence to diabetes medication(s). The findings were shared with culturally grounded organizations and community members as a means of confirmability; these community partners are invested in the health and well-being of African Americans. Thus, the strength inherent in triangulation of data was achieved through focus groups, individual interviews, and reviewing findings with culturally grounded community members (See Figure 9).

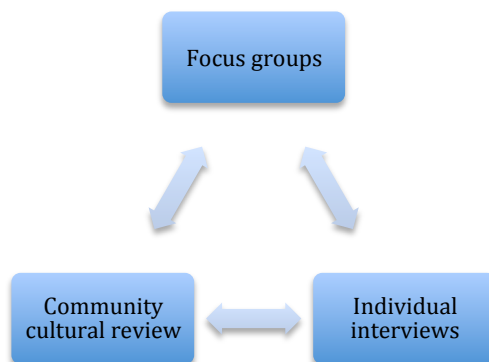


Figure 9. Triangulation of Qualitative Data

The resiliency conceptual framework created a structure for investigating protective mechanisms within four domains: the individual, the family, the community, and the broader society (Hill, 2007). To assist in identifying mechanisms associated with resilience, the concepts of competence, adversity, asset, and risk (Yates & Masten, 2004) were incorporated into the questions that guided discussion in both the focus groups and individual interviews (Appendix C).

Community-Based Participatory Research Approach

A Community-Based Participatory Research (CBPR) approach to the research study was utilized. Cornwall and Jewkes (1995) suggest CBPR is not a specific methodology, but “the attitudes of researchers, which in turn determine how, by and for whom research is conceptualized and conducted [and] the corresponding location of power at every stage of the research process” (p. 1667). Therefore, the researcher views CPBR as research that involves the community of interest at every stage of the research study and seeks to learn from the community how they perceive the question of interest and how the question can best be answered from within the community.

This study originated from within the African American community. While providing diabetes education in a hospital setting at the community level, the researcher had multiple opportunities to interact with African Americans taking prescription diabetes medication(s). The struggles and strategies related to adherence to diabetes medications were a topic of interest to many Black patients. Currently, the researcher provides information and support to African Americans with diabetes through her work with the American Diabetes Association’s community outreaches. Medication adherence remains a consistent theme for discussion. Furthermore, the researcher continues to

interact with health professionals who are involved in promoting healthier outcomes for African Americans with diabetes and they have expressed concern about improving medication adherence.

In this study, having important partners within the African American community was invaluable. Moreover, African American community partners vetted the focus group questions, strategies for focus group formation, and assisted with strategies for recruitment of participants. In addition, presentation of the findings was made to community partners as a means of confirmability of these findings. Therefore, medication adherence for African Americans with diabetes was based in the community and continues to involve the community in the entire research and dissemination process.

The researcher is not a member of the African American community and built rapport and trust within the community. Thus, extra care was taken by the researcher to be culturally sensitive; she asked probing questions to determine the meaning of an answer or concept from the African American perspective. The researcher visited communities that expressed interest in partnering in the research project numerous times and engaged support of partners within the African American community before conducting research. Efforts were made to build positive relationships with members of the African American community who have a stake in the research. Sharing findings with participants, culturally-grounded organizations, and community partners was done, as appropriate, taking care to achieve accessibility both physically and intellectually to community partners as was relevant to their needs and concerns (Minkler, 2004).

The Role of the Researcher

The role of the researcher in interviews and focus groups was one of facilitator and instrument (Creswell & Clark, 2011). Morgan and Krueger (1993) suggest competent group leadership can alleviate pressures of social status by emphasizing the goal of finding out as much as possible about participants' experiences and feelings on a given topic. Moreover, the facilitator/interviewer sought to create an open and accepting atmosphere in which each person had the freedom to share her or his point of view. Furthermore, while the researcher has extensive personal experience in managing diabetes, she does not assume that her experience is relevant for other people with diabetes.

The researcher is aware that the insider perspective in being a person with diabetes coupled with an outsider perspective of being white in a Black community poses both strengths and challenges. Moreover, gender differences created potential challenges. For example, when interviewing men, the outsider perspective was salient, as men were sometimes reticent to discuss this personal topic with a woman who was not known to them.

The decision to divulge the researcher's diabetes diagnosis was one made on an individual basis, as it could create additional barriers to information gathering or rapport, depending upon the individual being interviewed. For example, one man was not informed about the researcher's diabetes diagnosis at the onset of the interview and was guarded in his answers until the researcher shared this information with him; the interview proceeded with increased rapport and more detailed sharing from that point forward. However, the contrary was also observed, as informants would assume the

researcher already understood a particular concept or strategy because the researcher shared the diabetes diagnosis.

As a person with diabetes, the researcher was able to understand the difficulties of managing diabetes and probe for examples; however, she had to bracket her own experience in order to hear and understand the experiences of others. The researcher took care not to share her opinions, either verbally or non-verbally, with participants. While conducting the focus groups, the researcher intentionally engaged in bracketing to allow members of the focus group to answer questions according to their own definitions, sharing their experience without imposing the researcher's views (Creswell & Clark, 2011).

Moreover, it was important for the researcher to engage in reflexivity to consider how her ethnicity, gender, perspective, and personal experience of living with diabetes could influence the research and interpretation (Padgett, 2008). She engaged in documenting observations and feelings shortly after focus groups and interviews as a means of reflexivity and increasing self-awareness.

Human Subjects' Protection

All researchers involved in the study must verify completion of human subjects training within the past three years. The researcher received approval from Arizona State University's Internal Review Board (IRB) before conducting research (Appendix A). In addition, the researcher went through the process to be an Adjunct Research Associate (ARA) at Maricopa Integrated Health System (MIHS) and obtained a separate IRB approval from them (Appendix G). The primary mission of the IRB is to protect human

subjects; therefore, this process further reduced the possibility of harm for research participants.

The research study participants included adults who self-identified as African American, are diagnosed with Type 2 diabetes, and are adherent with their diabetes medication(s). Participation in focus groups and individual interviews was voluntary and the process of information letters or informed consent was thoroughly explained to all people who agree to participate in focus groups and interviews recruited through MIHS (Appendix H and I) and through other means (Appendix E and F). If the participant did not wish to be audio recorded, the researchers took detailed notes instead. Participants could decide not to participate at any point without penalty. Participants received a gift bag worth approximately \$25 donated by a local pharmacy chain.

The researcher honored confidentiality regarding all information shared in both focus groups and interviews. With focus groups, there is no assumption of confidentiality, as the researcher could not force others who are in the focus group to maintain confidentiality. However, with individual interviews, the researcher took reasonable precautions to protect the identity of the participant and maintain confidentiality regarding content. There were minimal risks to the participants as they were free to share whatever they were comfortable sharing; however, it is always possible that some may feel a degree of discomfort when sharing a particularly personal story.

Sampling

The qualitative research design collected data through three gendered focus groups with adults who self-identify as African American or Black. Additional inclusion criteria included (1) diagnosed with Type 2 diabetes; (2) currently on insulin therapy; and

(3) adherent to their medication(s) as assessed by four questions in the Simplified Medication Adherence Questionnaire (SMAQ) (Knobel et al., 2002; Moritsky et al., 1986).

The decision to use only those who are taking insulin limited the pool of potential participants as only 26% of those with diabetes are prescribed insulin (CDC, 2014); however, this decision allowed the richness of understanding the process of adherence to both OHAs and transitioning to insulin therapy. Diabetes is progressive; therefore, some people with diabetes who were able to obtain adequate glucose control with OHAs may require insulin over time (ADA, 2014).

Moreover, social determinants are related to health disparities; therefore, participants were asked about highest education level, category of income, and insurance status (Barr, 2008; WHO, 2010). This information was used to stratify sampling for individual interviews to represent a wider variety of income levels, educational attainment, and access to health care for participants.

Participants were recruited through gatekeepers who are well acquainted with the African American community. Flyers were distributed at community events and places that may attract the population of interest, as well as through email lists held by various organizations. In addition, the recruiter attended a number of community events (e.g. health fairs, bingo games, church services, women's expos) to recruit participants. A total of 35 people screened as eligible for the study and 23 agreed to participate. Primarily, participants were recruited from area Black churches (43%) and a healthcare center (30%) (Table 1). Only one woman contacted the recruiter as a result of receiving an email about the study; the remaining participants had contact with either a healthcare

worker, trusted acquaintance, or the researcher before being screened and participating in the study.

Table 1. Recruitment of Participants			
How/where recruited	Women	Men	All
Church	6	4	10
Healthcare center	4	3	7
Friend referral	2	2	4
Media email	1	0	1
Community event	0	1	1
Total	13	10	23

The researcher conducted the screening in three ways when contacted by an interested person: 1) in person; 2) over the telephone; or 3) by emailing a screening form. Once someone was determined to be eligible for inclusion, contact information was obtained and the person was invited to be a part of the focus group. If the person was unable to attend the focus group or preferred an individual interview, he or she was scheduled to participate in an interview at their convenience. Participants could not participate in both the focus group and the individual interviews.

The researcher sought variation on the demographics known to be associated with health disparities including education level, income, and access to healthcare. Sites for data collection were chosen based upon convenience for participants (Table 2).

Table 2. Focus Groups and Interviews Sites

Site	Women	Men	All
Individual Interviews			
Church	0	1	1
Community Center	1	1	2
Home	2	1	3
Public Library	2	3	5
Medical Facility	2	0	2
Office/Work	1	1	2
Focus Groups			
Church Weekend Day	2	2	4
Church Weekday Evening	2	0	2

Data Gathering Methods

Focus Groups

Data collection was conducted from August 2013 through September 2014. The focus groups included one men’s group and two women’s groups of two participants each. All focus groups were conducted at churches.

Focus groups do not carry the assumption of confidentiality, as the researcher cannot control what participants may share with others after the focus group discussion concludes and this was made clear in the informed consent (Berg, 2009). Informed consents were reviewed and given to all participants (Appendix E and Appendix I). In addition, a short questionnaire asking about length of time since diabetes diagnosis, insurance coverage, transportation to medical appointments, educational level, categorical income, and basic demographic information (e.g. gender, age) was administered prior to the focus group (Appendix B). The researcher provided light refreshments and participants recruited after gift bags were donated received them; otherwise, no compensation was provided.

“Focus groups may be best conceptualized as a research site, not a research instrument—a place where we can observe the processes of social interaction” (Hollander, 2004, p. 631). Krueger and Casey (2000) suggest, “The intent of focus groups is to promote self-disclosure among participants. We want to know what people really think and feel” (p. 8). Moreover, Hollander (2004) suggests a focus group is a specific social context in which members develop interpersonal relationships, which affect presentation of self; thus, gendering was an avenue to create a more comfortable setting for openness for participants. Furthermore, community partners suggested there may be differences in protective mechanisms, processes, or strategies used by men versus women; therefore, three gendered focus groups were conducted - one for men and two for women.

The focus group interviews were semi-structured with questions created using resiliency theory and an ecological perspective as a guide (Appendix C), remaining broad and general, allowing for variation in response and preventing leading of the informants (Creswell & Clark, 2011). The minimal structure of the questions allowed for the flexibility to explore unexpected responses, personal stories, and lines of discussion. Open-ended questions generated discussion and sharing of stories about the informants’ experiences with diabetes. Responses were repeated and summarized periodically to help participants to decide if there is anything missing from the discussion.

The researcher utilized focus groups to explore participants’ experiences in an interactive format (Lambert & Loiselle, 2008). Moreover, focus groups were particularly useful at uncovering macro level data, while individual interviews better illuminated more proximal, micro level data (Lambert & Loiselle, 2008). The primary goal of the

focus groups was to use interaction data resulting from discussion among participants to enhance the richness of data about aspects of the phenomenon that may be otherwise less accessible (Lambert & Loiselle, 2008). Focus group interactions served to accentuate participants' similarities and differences and provide information about the range of perspectives and experiences (Berg, 2009; Lambert & Loiselle, 2008).

Focus groups tend to be high in external validity as compared with other methods as they can mirror the typical conversations of participants (Hollander, 2004). Therefore, when forming focus groups, context was an important consideration. Understanding who has power and how that power may affect the discussion were imperative for optimal participation. The 90-minute focus groups drew upon the synergy of members, as participants responded to the comments of others in the group in addition to questions from the researcher (Berg, 2009).

The researcher reflected on Stevens (1996) analytical questions used to identify the nature of group interactions. These include: "How closely did the group adhere to the issues presented for discussion? Why, how, and when were related issues brought up? What statements seemed to evoke conflict?" (p. 172). These questions were discussed and answers were documented as part of the reflexive de-briefing process by the facilitator and co-facilitator.

The focus groups were viewed as a "site for analyzing the collaborative construction of meaning" (Hollander, 2004, p. 632). A social constructionist perspective suggests that people do not have stable underlying attitudes and opinions; rather, cultural norms and beliefs are constructed through the process of social interaction (Creswell & Clark, 2011). In this view, issues related to conformity, groupthink, and social

desirability do not obscure the data; instead, they become an integral part of the data because they are important elements of interaction within the African American community (Hollander, 2004).

Individual Interviews

Participants in focus groups were not considered for individual interviews. Recruitment for individual interviews used the same inclusion criteria used for the focus groups. Participants obtained through MIHS were provided with informed consent signed by both the participant and the researcher (Appendix H). Information letters per ASU IRB approval were reviewed and given to all other participants (Appendix F). The same questionnaire requesting personal information related to demographics and caring for diabetes was administered (Appendix B). The semi-structured interviews were conducted in quiet, private spaces. The settings included a room at a library, the participant's home, community centers, an office at MIHS, and the participant's place of work; it was important that the participant was in an environment that was comfortable for him or her. The interview elicited in-depth experiences from the participant and the interview lasted approximately one hour. A similar recruitment strategy was used and participants recruited after gift bags from a retail pharmacy were donated received them.

Focus groups and individual interviews were independent data collection methods; however, combining the data gathered provided corresponding views of the phenomenon of interest and enhanced description of the mechanisms that lead to adherence (Lambert & Loiselle, 2008). Integration of focus group and interview data involved an iterative process of uncovering data convergence and divergence

(Lambert & Loiselle, 2008). As themes emerged from the analysis of the focus group data, interview data was integrated into the overall analysis, producing a more complete picture.

There are two primary rationales for the combination of focus groups and individual interviews: (1) practical reasons, which provide alternative formats for gathering information to accommodate participants and (2) an integrated use, which strives to achieve data completeness and confirmation of findings (Lambert & Loiselle, 2008). Integration of focus group and individual interview data provided value through an iterative process whereby an initial model informed the guided exploration of group accounts and individual data further illuminated broad conceptualization of the phenomenon (Lambert & Loiselle, 2008). After analysis, the preliminary findings were shared with culturally-grounded community partners. Moreover, the convergence of core concepts of the phenomenon across focus groups, individual interviews, and vetting findings with community partners served to enhance the trustworthiness of findings (Lambert & Loiselle, 2008).

Content Analysis

As little is known about diabetes medication adherence in African Americans with diabetes, the theoretical lens of resiliency, guided content analysis. In addition, the study sought to understand cultural influences related to diabetes medication adherence and diabetes management; therefore the analysis utilized a social constructivist perspective. An assumption of social constructivism is that there is no one reality; various degrees of subjective interpretations can be applied to the same content (Creswell & Clark, 2011; Graneheim & Lundman, 2003; Miles & Huberman, 1994).

Moreover, it was important to understand diabetes medication adherence from the particular perspectives of the individuals who are experiencing this phenomena (Creswell & Clark, 2011).

A comprehensive literature review informed potential mechanisms associated with medication adherence. Then, content analysis of the focus groups and interviews examined language patterns used, as well as the particular contexts in which communication occurred (Berg, 2009). Furthermore, content analysis provided a coding and interpreting process, a detailed system of examining and interpreting data with the aim of identifying common patterns, themes, biases, and both manifest and latent meaning (Berg, 2009). Conventional content analysis involved the coding of categories derived inductively from the data for the purpose of generating resiliency based connections to the data (Berg, 2009).

The content analysis interpretive approach focused on both manifest content and latent content (Graneheim & Lundman, 2003). *Manifest content* refers to the more obvious, visible aspects of interpretation, whereas *latent content* involves interpreting the underlying meaning (Berg, 2009; Graneheim & Lundman, 2003; Miles & Huberman, 1994). Latent content analysis allowed for a deeper level of abstraction, a participant view of the phenomena going beyond the exact wording to interpreting what the informant intended to convey (Berg, 2009; Miles & Huberman, 1994). Moreover, a minimum of three independent examples to document the researchers' interpretations served as confirmability of latent meaning (Berg, 2009).

Process of Data Analysis

The volume of data generated by this study necessitated the use of technology to assist in organization and interpretation. MAXQDA software was utilized to assist in the organization and coding of the focus group and interview data. Weitzman and Miles (1995) state, “There is no computer program that will ‘analyze’ your data...Computers don’t analyze data; people do” (p.10). MAXQDA software provided an organizational tool with the capacity to assist the researcher in coding, retrieving, and connecting data (Berg, 2009).

The value of deductive reasoning based on the theoretical perspective of resiliency, ecological systems, and culture must be acknowledged; however, the researcher primarily employed an inductive approach to the data, allowing the presentation of the African American perspective to emerge from the data, while still facilitating the grounding of categories to the data (Berg, 2009).

Open coding, an inductive method of coding, served to open inquiry (Berg, 2009). Strauss (1987) suggests four primary guidelines when conducting open coding:

- (1) ask the data a specific and consistent set of questions;
- (2) analyze the data minutely;
- (3) frequently interrupt the coding to write a theoretical note; and
- (4) never assume the analytic relevance of any traditional variable such as age, sex, social class, and so forth until the data show it to be relevant. (p. 30)

Furthermore, Berg (2009) suggests viewing coding as a funnel; the process begins with a broad statement, and progressively narrows the statement with substantiated rationale until the small end of the funnel presents a refined conclusion. The ecological perspective provided a broad framework for coding, as the individual, family and friends, healthcare providers, and society became spheres for thinking about the content.

The researcher engaged in data reduction and interpretation by listening to the recordings and reading the voluminous data collected in the focus groups and interviews multiple times, while taking apart the data in order to create a consolidated picture of the phenomena (Creswell, 1994). Moreover, the researcher focused on the research questions to avoid time spent on other questions of interest for future study. The process of content analysis is depicted in Figure 10. The units of analysis for this study were focus group transcripts and individual interview transcripts, field notes, and researcher memoing. *Unit of analysis* refers to the specific objects being studied (Graneheim & Lundman, 2003); in this case, each transcript became a separate unit of analysis.

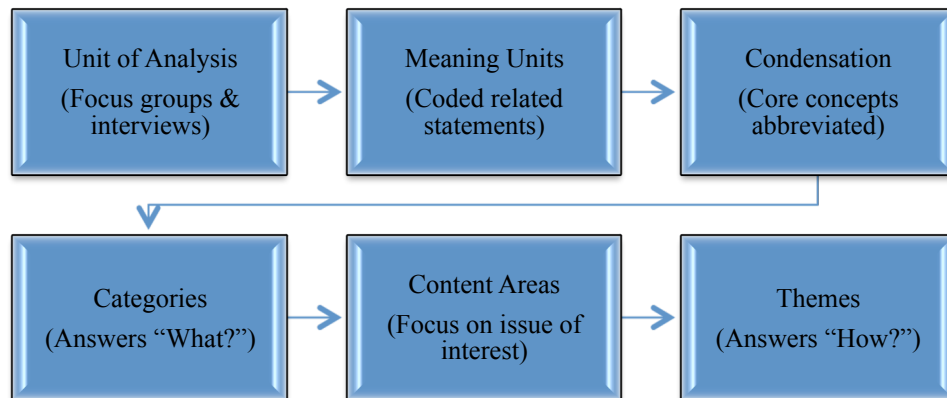


Figure 10. The Process of Content Analysis

From the unit of analysis a *meaning unit*, the assemblage of words, phrases or statements related to each other through a common content and context was derived (Graneheim & Lundman, 2003). A *code* refers to the label given to a given meaning unit (Graneheim & Lundman, 2003). Coffey and Atkinson (1996) suggest, “codes are tools to think with” that allow the data to be thought about in novel ways; however, meaning will be kept in context in order to preserve fidelity in interpretation (p. 32). Codes were

derived from literature. For example, support was coded according to who the informant identified as the one supporting the individual in medication adherence (e.g. spouse, friend, God, healthcare provider).

The next step in the analysis process included *condensation*, which is conceptualized as abbreviating while still maintaining the core concept (Graneheim & Lundman, 2003). The process of grouping condensed units under logical headings or *abstraction* includes the creation of codes, categories, and themes (Graneheim & Lundman, 2003). Open coding of categories was central to content analysis; a *category* is a cluster that shares commonality with other members of the same group (Graneheim & Lundman, 2003). Krippendorff (1980) suggests a category is used to answer the question of “What?” Categories were exhaustive and mutually exclusive meaning that no data was eliminated that was related to the category and no data was excluded simply because of an absence of an appropriate category (Berg, 2009; Krippendorff, 1980). The category provided a thread to connect the codes and was an expression of manifest content; categories were further divided into sub-categories (Graneheim & Lundman, 2003). Axial coding, which related categories with concepts, occurred after open coding and consisted of rigorous coding within one category (Strauss, 1987).

The specific domains are referred to as content areas since there was a focus on a particular issue of interest (Graneheim & Lundman, 2003). *Content areas* are portions of the text grounded in theoretical assumptions in existing literature or a section of text that addresses an uncovered topic (e.g. support). Finally, a *theme* refers to threads of meaning that recur in the content areas (Graneheim & Lundman, 2003). The theme answers the

question, “How?” (Graneheim & Lundman, 2003). Themes were expressions of latent content as they were examining the underlying meaning; themes were further divided into sub-themes, as necessary (Graneheim & Lundman, 2003). Themes may be gendered; for example, support was very different by gender, as “nagging” was interpreted as care and love to many men and it was interpreted as criticism to many women.

Moreover, representative quotes from participants were observed to cluster according to similar characteristics (e.g. gender, illness perception, support) through an iterative process (Wachholz & Stuhr, 1999). In addition, a procedure for identifying common classes to distinguish among and between persons was used. The categories were essential to ascertain whether certain demographic characteristics (e.g., gender, age, education level) were related to patterns observed in the data (Berg, 2009).

Psychotherapy research refers to this process as qualitative cluster analysis (Wachholz & Stuhr, 1999). This clustering was used to detect emerging typologies, which provided ways of identifying multiple pathways to medication adherence and the identification of four distinct typologies with at least three people in each group.

Data Interpretation

The research question was central in the process of data interpretation, which entailed the development of ideas related to the data through the theoretical lens of resiliency (Berg, 2009). The goal was to illuminate and clarify how the perspectives of participants were related to the broader literature on medication adherence in African Americans. Berg (2009) suggests content analysis is a “passport to listening to the words of the text and understanding better the perspective(s) of the producer of these words” (p. 343). The process of data collection, data interpretation, data analysis, and writing the

results were conducted simultaneously (Creswell, 1994). Negative case analysis was utilized to verify a given hypothesis (Berg, 2009). This strategy involved intentionally seeking to disconfirm a given hypothesis by exploring examples that challenge the hypothesis (Berg, 2009). For example, if the Black church were hypothesized to be an asset to resiliency, and evidence to the contrary (e.g. little or no support was identified by participants) then this would disconfirm the hypothesis.

The data were presented in matrices, visual displays of information that represented the data in a spatial format (Creswell, 1994; Miles & Huberman, 1984). The matrices display categories by participants and demographic characteristics. In addition, relationships between data were demonstrated in narrative and visual formats. This enabled clustering of themes, categories, and demographic similarities to be observed, as commonality within gendered groups were identified; thus, the fur emerging typologies became evident.

Trustworthiness

Qualitative research uses the terms credibility, dependability, and transferability to describe aspects of trustworthiness. *Credibility* refers to assurance of how faithful the researcher(s) have been in the process of data analysis (Graneheim & Lundman, 2003). Credibility begins long before data has been collected; the researcher made decisions about the appropriate theoretical lens, selection of participants, recruitment protocols, and ethics in carrying out the research design, which all contribute to the credibility of the study (Berg, 2009; Creswell & Clark, 2011). Choosing diverse participants who had a unique perspective and could provide rich information about the phenomena under investigation was imperative to credibility.

Moreover, credibility was derived from how well the categories and themes cover the data in that no relevant data were excluded as well as determining similarities and differences between categories (Berg, 2009; Graneheim & Lundman, 2003). The researcher created an audit trail that clearly delineated how decisions were made concerning categories and disagreements between coding (Creswell, 1994).

Representative quotations from a minimum of three distinct participants were used to support the category or theme (Berg, 2009). The integration of the data collected from both focus groups and individual interviews served as a productive strategy to better understand the phenomenon and characteristics associated with resiliency in medication adherence. Since multiple realities exist for individuals, perfect agreement on category and thematic choices was not the goal; rather the goal was to create a consistent process used to label and sort data (Berg, 2009; Graneheim & Lundman, 2003).

Participants and other members of the African American community were asked to review the findings as a means of *confirmability*, or the degree that the findings can be corroborated by others within the cultural community (Berg, 2009; Graneheim & Lundman, 2003). This is consistent with a CBPR approach, which encourages engaging the community in the research at every level including sharing with the community what strategies and supports have been uncovered through the research process. Discussions concerning initial findings were held with individuals and pairs within the community to determine if the researcher was interpreting the data correctly. The cultural community partners often asked probing questions of the data. For example, one partner asked how long participants had been diagnosed with diabetes in order to better understand how time impacted the acceptance of the diagnosis and medication adherence. Moreover,

community cultural partners vetted the emerging typologies and were invited to provide descriptive names for these typologies.

Trustworthiness also includes the aspect of *transferability*, or the degree that the research can be extended or transferred to similar communities (Graneheim & Lundman, 2003). A detailed description of the sample, including the demographics of interest, was necessary to determine for whom the findings are relevant in order to assess transferability. Choosing appropriate quotations from the text that represent the cultural and contextual characteristics of the sample enhanced transferability (Graneheim & Lundman, 2003). Ultimately, the reader will decide if the results are applicable to broader populations outside of African Americans living in the Southwest.

Chapter 4

RESULTS

This study is guided by the broad research question, “What mechanisms are associated with adherence to diabetes medication(s), including insulin, for African Americans?” This research question is operationalized through two primary aims:

Aim 1: To examine what individual and broader environmental mechanisms are associated with adherence to diabetes medication(s) for adult African Americans with Type 2 diabetes.

Aim 2: To identify internal and external factors that enable African Americans with diabetes to go beyond adherence and to develop a broader understanding of the disease and how to manage it.

Rutter and Sroufe (2000) suggest, “mechanisms involved in causation might entail dynamic processes operating over time, that indirect chain effects might often be present, and that there might be several different routes to the same outcome” (p. 268). As much as possible, a discussion of context and process will be included to provide a deeper understanding of the findings from the focus groups and interviews.

Participant Demographics

Twenty-three people participated in focus groups and interviews. There were 17 participants in individual interviews and six participants in gendered focus groups. The sample was diverse in demographics including age (36-80 years), income, education, and marital status with men being more likely to be married than women. Furthermore, diabetes-related information confirms the majority of informants (83%) participated in DSME at least once. There was variation in insurance coverage with most participants

having AHCCCS (8), Commercial (7), or Medicare (6). Other demographics of the sample varied considerably by gender.

There were a total of thirteen female participants; nine participated in individual interviews and two women were in each of two focus groups (Table 3). The mean age was 59.35 with a range of 36-79 years. Five women were married. Most participants completed college (8). Most women in the study had family income of \$50,000 or less (11).

Table 3. Female Participant Demographics

*Participant	**Age	Highest Education Completed	Family Income Category	Marital Status
Gina	36	College	>\$75,000	Married
Julia	45	High School	<\$25,000	Single
Carrie	53	College	\$25,000-\$50,000	Single
Laura	56	High School	>\$25,000	Married
Marie	60	High School	>\$25,000	Single
Vanessa	62	College	\$25,000-\$50,000	Married
Alice	64	College	\$25,000-\$50,000	Single
Lucy	70	<High School	<\$25,000	Single
Annie	79	College	<\$25,000	Single
Focus Group Participants				
Renee	43	High School	<\$25,000	Single
Jeannie	77	College	\$50,000-\$75,000	Married
Monica	55	College	<\$25,000	Single
Gloria	64	College	\$25,000-\$50,000	Married

*Pseudonyms were given to protect confidentiality

**Age at time of interview/focus group

There were a total of ten male participants; eight participated in individual interviews and two men were in the focus group (Table 4). The mean age was approximately 58.9 with a range of 38-80 years. Most men were married and half of participants completed college. Half of participants had a family income of \$50,000 or less.

Table 4. Male Participant Demographics

*Participant	**Age	Highest Education Completed	Family Income Category	Marital Status
Bret	52	College	\$50,00-\$75,000	Married
Anthony	55	High School	<\$25,000	Single
Fred	72	High School	\$50,00-\$75,000	Married
Greg	40-50	College	No answer	Married
Denzel	55	College	<\$25,000	Single
Andrew	57	<High School	<\$25,000	Single
Harry	60	College	>\$75,000	Married
Charlie	80	High School	\$25,000-\$50,000	Married
Focus Group Participants				
Jack	38	High School	<\$25,000	Married
Ernie	61	College	>\$75,000	Single

*Pseudonyms were given to protect confidentiality

**Age at time of interview/focus group

Female participants reported mean time since diagnosis of diabetes as 19.5 years with a range of 5-35 years (Table 5). Moreover, women were diagnosed with diabetes at an average of 41.4 years old; most were between 33-54 years old at diagnosis. The majority of women reported no diabetes-related complications. Furthermore, the majority of women participated in a diabetes self-management education program (DSME) at some point since diagnosis. One woman, Alice, had no insurance coverage. Four women were on Arizona Health Care Cost Containment System (AHCCCS), which is Arizona's Medicaid program. Four women received commercial medical insurance through their

employer and four women were on Medicare. Female participants overwhelmingly chose to get prescriptions filled at the pharmacy; the exceptions were Vanessa whose husband took care of ordering medication for her and had it delivered by mail and Gina who got most prescriptions filled at a retail pharmacy and one medication through a mail order pharmacy.

Table 5. Female Participant Diabetes-related Information

*Name	Age at diagnosis	Years of diabetes	Medication Type	DSME	Complications	Insurance	Prescription Acquisition
Gina	30	6	Insulin & OHA	Yes	No	Commercial	Both**
Julia	38	7	Insulin & OHA	No	Yes	AHCCCS	Pharmacy
Carrie	48	5	Insulin & OHA	No	Yes	AHCCCS	Pharmacy
Laura	21	35	Insulin only	Yes	No	AHCCCS	Pharmacy
Marie	38	22	Insulin only	Yes	Yes	AHCCCS	Pharmacy
Vanessa	50	12	Insulin & OHA	Yes	No	Commercial	Mail Order
Alice	42	22	Insulin & OHA	Yes	No	None	Pharmacy
Lucy	54	16	Insulin only	Yes	Yes	Medicare	Pharmacy
Annie	53	26	Insulin only	Yes	No	Medicare	Pharmacy
Focus Group Participants							
Renee	24	19	Insulin & OHA	Yes	Yes	Medicare	Pharmacy
Jeannie	72	5	Insulin & OHA	Yes	No	Medicare	Pharmacy
Monica	33	22	Insulin & OHA	Yes	No	Commercial	Pharmacy
Gloria	35	29	Insulin & OHA	Yes	Yes	Commercial	Pharmacy

*Pseudonyms were given to protect confidentiality

DSME=Diabetes Self-Management Education

AHCCCS= Arizona Health Care Cost Containment System

**Both=Retail pharmacy and mail order

Male participants reported mean time since diabetes diagnosis as 15.4 years with a range of 2-26 years (Table 6). Moreover, age at which men were diagnosed was an average of 43.6 years old; range of 32-57 years old at diagnosis. Participants were evenly divided in the type of diabetes medication they took; half took insulin only and the other half took both insulin and OHAs. Most men reported no diabetes-related complications and the majority of men participated in DSME one or more times since diagnosis. Four

men received care through AHCCCS, three men received commercial medical insurance through their employer, two men received healthcare benefits through Medicare, and one man received military health benefits through Tricare. Prescription acquisition was primarily through pharmacies, with three men using the mail order option.

Table 6. Male Participant Diabetes-related Information

*Name	Age at diagnosis	Years of diabetes	Medication Type	DSME	Complications	Insurance	Prescription Acquisition
Bret	38	14	Insulin only	Yes	No	Commercial	Pharmacy
Anthony	32	23	Insulin only	No	Yes	AHCCCS	Pharmacy
Fred	57	15	Insulin only	Yes	No	Medicare	Pharmacy
Greg	26-36	14	Insulin & OHA	No	Yes	Commercial	Pharmacy
Denzel	38	17	Insulin & OHA	Yes	Yes	AHCCCS	Pharmacy
Andrew	55	2	Insulin & OHA	Yes	No	AHCCCS	Pharmacy
Harry	45	15	Insulin & OHA	Yes	No	Tricare	Mail Order
Charlie	54	26	Insulin only	Yes	No	Medicare	Mail Order
Focus Group Participants							
Jack	35	3	Insulin & OHA	No	No	AHCCCS	Mail Order
Ernie	46	15	Insulin only	Yes	No	Commercial	Pharmacy

*Pseudonyms were given to protect confidentiality
 DSME=Diabetes Self-Management Education

Categories and Themes

Furthermore, it is important to note that all participants were screened based upon adherence to diabetes medication and not necessarily adherent in all areas of diabetes self-management (e.g. diet, activity, blood glucose monitoring). In fact, very few participants reported being adherent with all facets of diabetes self-management. Many admitted to having difficulty eating a healthy diet and many reported not engaging in enough physical activity. Concerning consistency in taking her medication, Vanessa summarizes the thoughts of those who take their diabetes medication and struggle with changing lifestyle habits, “At least I'm doing one thing right!”

Ecological systems and resiliency lenses provided a theoretical framework for viewing data to examine individual and broader mechanisms associated with diabetes medication adherence in this population. Data were approached by open coding meaning units that were condensed and categorized and working toward more specific themes (Table 7). Condensation revealed the broad areas discussed while further investigation saw emerging categories and themes within these condensed areas.

Table 7. Categories and Themes Derived from Data

Illness Perception	<ul style="list-style-type: none"> • Sense of stigmatization within community • Acceptance of diagnosis • Awareness of seriousness of diabetes • Conceptualization of diabetes • Personal locus of control and empowerment
Support	<ul style="list-style-type: none"> • Family and friends • God • HCPs • Insurance
Process of Medication Adherence	<ol style="list-style-type: none"> 1. Seeing a HCP 2. HCP writes prescription 3. Pharmacy fills prescription 4. Pick up prescription 5. Understand dosing instructions 6. Follow dosing instructions 7. Overcome fears and side effects 8. Repeat process when new prescription needed

The major themes discussed will include illness perception, support, and the process of medication adherence. Illness perception will include stigmatization, acceptance of diabetes diagnosis and awareness of the seriousness of diabetes. Major

sources of support included family and friends, God, HCPs, and insurance. Furthermore, four gendered emerging typologies were identified, which may further illuminate major themes.

“Diabetes is One of those Stigmas” (Harry)

People who do not have diabetes often do not perceive diabetes to be a stigmatized condition; however, many of the people with diabetes in this study reported feeling judgment, shame, and unwanted interference in their lives. A seminal author in the conceptualization of stigma, Goffman (1963) defines stigma as an "attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted discounted one" (p. 3). Link and Phelan (2001) further describe stigma as the “occurrence of its components –labeling, stereotyping, separation, status loss- and further indicate that for stigmatization to occur, power must be exercised” (p. 363). Furthermore, many researchers suggest that stigmatization is capable of affecting the health and well-being of those who are stigmatized (Bock, 2012; Link & Phelan, 2001; Schabert, Browne, Mosely, & Speight, 2013). Bock (2012) suggests, “Stigmatizing storylines occur when stereotypical categories overdetermined individual identities” (p. 158). This can be heard in informant Jeannie’s comment, “Just don't drop me into that pot with everybody, you know.” She expressed determination to be treated as an individual and not stereotypically labeled as an obese diabetic.

A major challenge in recruitment for this study was the perception of diabetes-related stigmatization in the African American community. Church health ministers, Black nurses, and others invested in the health of African Americans seldom knew someone who had diabetes, let alone someone who was taking insulin, which alludes to

the reluctance to discuss the prevalent diagnosis. Furthermore, many people in the community (e.g. church members, African American healthcare workers) were hesitant to invite people they knew had diabetes to participate because “I don’t want to get in their business.” Discussions with HCPs about potential patients to participate in the research study often resulted in resistance. For example, one primary care physician declared, “There aren’t any patients who are adherent.” Prolonged engagement with an organization or group was necessary in order to build adequate rapport and trust enabling people with diabetes to feel safe volunteering to be screened for the study.

On one occasion, a Black woman in her 80s, who was well known to the researcher, approached and whispered, “I have diabetes if that will help.” She was not taking insulin; thus, she was not eligible for the study. On two occasions, the researcher presented the study to a professional organization concerned with African American health. Upon the conclusion of each presentation, several members of the group approached the researcher and declared, “I like your study. I just wish I knew someone with diabetes.”

Moreover, when asking community members about why an African American may not want to reveal he or she has diabetes, the common reply was related to revealing a “weakness” or “vulnerability”, and not wanting to be a “burden” or “looked down on”. These responses from the larger community suggest a loss of status associated with a diagnosis of diabetes. This sense of weakness associated with diabetes was salient, particularly for some women in the study. Another community partner expressed concern about the stigmatization of a medical diagnosis in the African American community, “When are we going to start talking about our medical conditions?”

Many participants discussed telling their mothers about being diagnosed with diabetes and hearing for the first time about a family history of diabetes. Ernie discussed finding out his mother had diabetes, “I never knew, because I don't think she became a diabetic until she was about the age I am now, about 62 years old.” In talking about his own diagnosis, Ernie discovered a family history of diabetes, “And my grandmother, she [mother] told me, was a diabetic also, and I said, ‘I didn't know that.’” Julia discovered a family history of diabetes at a family gathering about a year after she was diagnosed, “I started hearing that everybody else had diabetes. I didn't know.” She recalled the extent to which her family was diagnosed with diabetes, “My mom, and I have a cousin who's diabetic and her brother.” Vanessa recalled, “I know I started talking to Momma when I found out about it [diabetes] and maybe that's when I found out. I don't know that much about my family history.”

For most participants this discovery was a shock and they determined to tell their children about the extensive family history of diabetes. For example, Vanessa engaged in regular conversations about diabetes with her children. “We talk openly about it, and because I want my kids and the rest of my family to know that, sure, heredity plays a lot, but environmental factors I think weigh even heavier.”

Some informants were highly aware of obesity-related stigma, which often extended to a diagnosis of diabetes, suggesting that the judgment they experienced may be related to their size and their diabetes diagnosis. One women’s focus group discussed the impact of weight on how people, including medical professionals, treated them.

Renee revealed:

It bugs me that they can look at me and tell [she has diabetes], because — I guess that's because the doctor who initially told me that's what she did, and it's like, what are you basing it on, you know? I was downright offended! Well, you know what it was, and I'll be very honest with you. Because she said, when she was explaining it to me, she was saying because of my weight.

When asked if medical professionals label or judge based on size, Jeannie added, “That's what I'm seeing now. That is the way society works.” Furthermore regarding negatively stereotyping those who are obese, Jeannie stated, “Then they [medical professionals] drop us all into the same pot, and that's what I'm getting from what she's [Renee] saying, you know. Just don't drop me into that pot with everybody, you know.”

Even participants like Harry who were open and willing to talk about diabetes with others were keenly aware of the stigmatization of diabetes,

There's nothing to be embarrassed about to being a diabetic. Because I think in the African-American culture there are some stigmas to certain things, and, believe it or not, diabetes is one of those stigmas, and I don't know why, but it is.

He goes on to posit why talking about diabetes is taboo within the African American community,

I really don't know, because what diabetes is, I mean, it's not, you know, it's not one of those, I don't know, it's not an STD or anything like that. You know what I'm saying? So it's just something that, you know, it's something that happens, so I just don't understand why folks don't like to talk about being diabetic. I just don't — obviously I'm not one of those.

Charlie alludes to the stigma present in the African American community and his desire to be more open about talking with others, especially his family, about diabetes, “Well, the family, the children, all the kids know [about his diabetes diagnosis]. It never was something we were ashamed of. It's a black man's disease.” Charlie has been open with his family about his diabetes and encourages his sons to get checked.

Gina suggested another reason for people being hesitant to divulge a diabetes diagnosis, “But I just think it's, like, the whole diabetes police coming out again and, like, monitoring you.” For her, this is not an issue; she viewed the additional attention as people caring about her.

“I have to accept in order to live” (Alice)

From the very beginning, some informants accepted the diagnosis of diabetes and were adherent to medication, “I have no problems at all accepting my diabetes, because it's something I have to accept in order to live” (Alice, diagnosed 22 years ago). Bret summarized his attitude this way; “The whole is simply this for me. I found out that I have Type 2 diabetes. They gave me medication. They said I must take it on a daily basis. I'm going to take this medication every day.”

Moreover, Bret understood the need to manage diabetes from watching other African Americans not take diabetes seriously,

I understand that in my culture that many have diabetes, and they don't take it seriously. I took it seriously from standpoint that they [physician] said, ‘Hey, this disease can cause you to go blind, heart attack, and it's a silent killer.’ You may not even know that you have it. When you find out about it, it's too late.

Bret engaged in prevention by having a physical twice a year. He believed this practice helped him to be diagnosed early and prevent complications from poor glucose control. Moreover, he quickly learned about diabetes self- management, “So I had to educate myself and get educated about diabetes. So I read everything that I could possibly read about it, then I took control of my diet.”

Others reported denial and, thus, non-adherence to their medications after diagnosis. “So I was in denial at first. I don't have it [diabetes]” (Julia, diagnosed 7 years

ago). In fact, Julia did not tell anyone except her mother about her diagnosis for about a year stating, “Why should I talk about it [diabetes]? I don’t got that, you know?” Julia’s initial blood test revealed an extremely high blood sugar of about 350 mg/dL; normal blood sugar would be below 100 mg/dL. She was given a prescription for oral hyperglycemic medication, “I didn’t take it, because I was, I don’t — this is not for me.” She explained, “I got it filled, but I didn’t feel bad. I felt fine, so I’m like what are they talking about? I don’t have no, you know, but then when I started getting, learning more about it.” After about a year, Julia discovered that many of her relatives have diabetes and some have experienced serious consequences from not adequately controlling blood sugar. She decided to tell them she has diabetes as well. At this point, she began to take her medication regularly, “I have to. I have to.”

Renee (diagnosed 19 years ago) was initially in denial, “I figured that it [diabetes] would go away. I did. I figured it would go away, because I’m Renee, you know.” Renee was forced to tell people about the diagnosis; however, she struggled with accepting the diagnosis stating it took her 6 months to a year to accept she had diabetes.

I really didn’t take it seriously when they first gave me the medication, because, like I said, they were giving me 2 mg of Amaryl, and I’m like, so you want me to take this little itty bitty little pill and cut it in half? Darn diabetes! Leave me alone. Why are you messing with me, you know?

Moreover, she minimized the seriousness of the diagnosis, “I thought, you know, it was as if to say taking just half of a teeny tiny pill it can’t be that serious. I didn’t think my condition was as serious, you know.” Through a process of learning more about diabetes, she accepted the diagnosis and now states, “Now it’s just old hat to me.”

Jack was diagnosed with diabetes three years ago and initially struggled with taking diabetes medication. He had a desire to go “back to being normal without having to live my life to take a pill every day or to get a shot every day.” He goes on to reflect, “It [taking medication] used to be a downer, like, okay now I've got to take that. I've got to get up and take this medication.” He still hopes to “beat it [diabetes]” and not have to take any medication to control his blood sugar, but is resigned that diabetes medication is necessary for him to be healthy at this point in time.

Other informants were adherent with their medication from the beginning. “I'm one of these people that believes what the doctor says ... and if they say that I need the pills or the shot or whatever, I take it religiously” (Vanessa). Harry grasped the diagnosis of diabetes from the very beginning, “I've got to accept it and find out what do I need to do to control it now. This is going to be a lifelong thing for me now, so I have to learn how to live my life having diabetes.”

The transition from taking OHAs to including insulin therapy presented additional challenges to medication adherence for many participants. For example, when Bret reflected on the conversation with his doctor about needing to take insulin, he recalled, “That was a rough conversation between me and my doctor.” Bret remembered the physician informed him that, “You're going to now be on Lantus [long-acting insulin], and you're going to have to stick yourself 20 units at night.” He shook his head in disbelief and stated, “I heard what she said. I don't think I comprehended what she said.” He clarified the need for insulin shots, “Is there anything else that you might have or something else that you can prescribe, because you're talking about literally poking me?” His doctor of fifteen years confirmed the need for insulin and suggested he try it for three

months. She confirmed the necessity of this treatment by telling Bret, “This is going to help you live.” Bret learned how to administer the pen injections before leaving the office and confirmed, “It [insulin] has helped me. Much better than I did when I was taking the pills.”

Denzel equated initiating insulin therapy with a terminal illness,

It's almost like the doctor telling you, ‘We're going to have to send you to the hospice.’ This is that serious, you know, being on insulin. And I thought, okay, they say you're on insulin the rest of your life.

Greg was somewhat fatalistic, “guaranteed the disease is going to progress.” Greg fears that if he does not take his diabetes medication, “You might develop new symptoms.” He goes on to state he fears even worse, “or indications, signs of the disease progressing. So it may not be discernible to you immediately, but over time, if you do nothing, you're going to degrade. Your condition is going to degrade.”

While some participants readily accepted the diabetes diagnosis, others were initially in denial and, therefore, did not see a need for taking their medication. The process of acceptance often involved an understanding of their family medical history concerning diabetes. Ultimately, acceptance of the diagnosis was instrumental for all informants when it came to taking their diabetes medication consistently. Alice discussed her understanding of diabetes:

You can't get rid of that [diabetes], and see, they tell you that. They say once you're a diabetic, you are always a diabetic. When you face that reality when someone tell you that you are a diabetic, you say, “Oh my God. For the rest of my life I've got to be a diabetic?” I've got to take medication.

Alice confirms her need for diabetes medication, “You also look at the lab work and that helps you know that your meds are helping.”

Healthcare Providers: Pharmacists

While support from others (HCPs, family, friends) varied according to gender and personal preference, participants consistently reported the value of their pharmacist in diabetes medication adherence. When informants were asked how they obtain their medications, the vast majority stated they go to the pharmacy (83%) every month to pick up their prescriptions versus those who utilize mail order pharmacy services (17%). The sense from those who preferred to go to the local pharmacy was one of choosing control and engagement over convenience cited by mail order pharmacy proponents.

When asked if they have the option for mail order pharmacy, many people said they do have that option; however, their preference was to go to the pharmacy on a monthly basis anyway. The reasons for this choice fell into the following categories: 1) they get refill reminders; 2) they have a beneficial professional relationship with their pharmacist; 3) it is part of their routine; 4) problem solving is easier in person; and 5) they could obtain free diabetes information.

Many participants were grateful for the automated reminders to get refills of their medication. This process was made a bit easier for them when they received a reminder notification and could call the pharmacy to order their medication.

Patients felt they benefitted from a relationship with their pharmacy personnel. For example, Ernie stated,

Everybody in that dadgum store knows me... and if I go to another city — this has happened more than once — the pharmacy in the other city may not fill the prescription, and then I'll have them call my pharmacy, and they'll say, oh yeah, fill his prescription.

Monica saw a benefit in a relationship with her pharmacist, “the pharmacist knows me, I just establish a rapport with them [pharmacy personnel], and I haven't had a problem.” Several informants spoke glowingly about their pharmacist. Carrie declared, “I love my pharmacist. Lou's my guy!” Anthony looks forward to seeing his pharmacist, “I'm in a habit. I'd just rather go down there and pick it [prescription] up, because I get a chance to see him [pharmacist] and talk to him and, you know.” Others spoke about obtaining specific information from their pharmacist that helped them take their medication or prevented a problem. For example, Carrie credits her pharmacist with preventing a serious drug interaction,

He's, like, “you taking too many medications that will have an adverse reaction to this medication. So I'm going to call your doctor and let them know that I don't know why they prescribed this, but they need to prescribe something else, because you can't take this.” So he really knows me. He has my history since, like I said, since I've been diagnosed.

Gloria related a similar encounter with her pharmacist, “He [pharmacist] says, ‘you know, it's not likely, but we don't want to push it, but based upon what you're taking, this medication is known to cause seizures.’ I was so grateful!”

Routine was cited as a reason to go to the pharmacy to obtain prescriptions even if they had a mail order option. Many people seemed to adopt the “if it is not broken, do not fix it” mentality. Anthony stated he had a mail order option, but he preferred to obtain his prescriptions from pharmacy across town, “I don't have no problems with them [pharmacy across town].”

Gina got most of her prescription medication from her local pharmacy, but obtained one through mail order. When asked why she does not get all of her prescriptions in one place, she replied, “So it's close, and I have to go there anyway to

pick up my son's prescription.” She simply never considered transferring all of her prescriptions to one source.

Others told stories about how their prescription medications were not correct and it was possible to fix the error in a timely manner when they were at the pharmacy; they could not imagine the difficulty if a mail order pharmacy were involved. Renee believed she can prevent mistakes with prescription refills by reconciling the order with the list on her phone before leaving the pharmacy, “well they [pharmacy personnel] bring it to me, and before they ring it up I go and check my list against what they have.”

Annie kept a spreadsheet of what medications cost and where she can purchase them for the least amount of out-of-pocket cost and shopped for lower prices at different pharmacies, “So I started getting it [one of her diabetes medications] at Store A, because if I get it at the regular drug store it's more expensive than at Store A.”

Many people enjoyed picking up the free health-related magazines and other written information while picking up their prescriptions. In addition to this form of information gathering, a few were even more assertive and posed questions to their pharmacist about diabetes management. For example, Carrie learned about the danger of getting scar tissue associated with giving her insulin shots in the same place from her pharmacist, “He said, don’t do it [insulin shot] in the same spot every day. Alternate. Do it in your hips, stomach, arm, then go down, arm, stomach, hip, then go back again, hips...” Her doctor confirmed this information two months later.

Those who favored the mail order pharmacy cited the convenience of not having to be involved in the process of medication acquisition. Typically, the HCP called in the prescription and the mail order pharmacy took it from there; patients received their

medication in a few days. Insulin arrived in a cooler and no one in the study had a problem with getting tainted insulin. Harry believed obtaining his diabetes medication through mail order has helped him to be adherent, “Because before I started doing the mail order, I would have to go to the pharmacy, and sometimes I would forget and then I'd run out.”

While perception of stigma and acceptance of the diabetes diagnosis were common among all participants, other perceptions varied according to gender. For example conceptualization of diabetes and, thus, orientation toward self-management differed according to gender and other demographic factors that clustered within emerging typologies. Furthermore, support from others changed according to personal preferences and perceptions and personal definitions of support. For example, preferences and expectations for HCPs and the ensuing relationship with various HCPs differed according to gender and typology and were seen to be on a continuum from compliant to somewhat resistant at times. The explorations of these emerging typologies provides an avenue for discovering variations in mechanisms that result in medication adherence, as there are several paths to diabetes medication adherence.



Gender: Emerging Typologies for Black Females

For Black women there were two distinct emerging typologies (Table 8). The “Alpha” females were mostly college-educated women who viewed themselves as “independent,” “strong,” and “self-sufficient.” When Alpha women were asked about who helps them with their diabetes, many appeared confused by the question. The first answer was usually, “my doctor” and, if pressed, some offered God as a support. These women had high expectations for their HCPs and told stories about being highly assertive

in their medical care. It was not unusual for Alpha women to talk about a doctor who was not “invested in my health” getting “fired.”

In contrast, “Networking” women had a support system that extended beyond HCPs and God to friends, family, and co-workers. These optimistic women welcomed the support of others and found it relatively easy to talk about their diabetes with other people. Their focus was on creating an increasing support system with healthcare professionals and others who could help them to manage diabetes and learn more.

Table 8. Emerging Typologies for Diabetes Medication Adherent African American Women

Alpha Women		
	Characteristic	Representative Quote
 Alice Annie Carrie Gloria Renee	Diabetes is a vulnerability or weakness	“This is my healthcare, not theirs [doctors]. I have to be here, so you're not going to play with my healthcare!”
	Identify as strong, self-sufficient, independent	“I get all my questions answered.”
	Primarily college educated	“We [sister and her] know something about it [diabetes], so why discuss it?”
	Low social support for diabetes management	“I just don't want to talk about it [diabetes]. Bring it up for what?”
	High expectations for HCPs “invested in my health”	“I've learned that no one else can help you when you get into your own physical, emotional thing.”
	God is an important support	“What can man do to help me out?” “I'm a very religious person, and I go to God, you know, when I have really serious problems.”
Networking Women		
 Gina Lucy Marie Monica Vanessa	Diabetes is a part of their lives	“Diabetes doesn't have me.”
	Optimistic, amiable, focused on building rapport with others	“I thank the Lord that He has doctors.”
	Feel “cared for” by their HCPs	“I just establish a rapport, not only with my doctors, but with the pharmacist.”
	Extended support system (HCPs, God, friends, family, co-workers)	“I'm like an open book. Anybody that wants to know.”

Alpha Women: “What can man do to help me?”

These strong, independent women were primarily single; the Alpha woman who was married described her relationship with her husband as somewhat distant. When speaking about diabetes, Alpha women expressed a sense of being invaded by an unwanted intruder. Carrie felt betrayed by her once healthy body, “How could my body reject my insulin? What the heck? So now, you talk about betrayal. That was a big betrayal.” She goes on to state that she always took good care of this “vessel”, “Never did drugs. Don't drink alcohol. Always exercised. I'm, like, and this is what you do? ... I mean, what was the reward? Oh. Hey. Guess what? I'm not going to produce any insulin for you.”

Many Alpha women were keenly aware of someone they know who experienced severe complications or someone who died as a result of diabetes-related complications. Alice shared her understanding about what could happen if she does not take her medication, “Because if you don't take your pills you will die, because you will go into a stroke. Your sugar go up so high, you stroke, heart attack, I mean, why go through those changes if you don't have to?” Carrie discussed the importance of taking her diabetes medication, “I know that I have to do it [take medication]. I have to do it, or I could end up like my brother.” Sadly, Carrie’s brother died at a young age from diabetes-related complications.

These women had stories about poor relationships with HCPs; thus, had strong opinions about what a good relationship with a physician entailed. Their expectations for HCPs included being “invested in my health.” In fact, many Alpha women were extremely meticulous in their record keeping and prepared for their doctor visits; many

Alpha women brought in detailed blood sugar logbooks, which included food diaries.

Annie kept an Excel spreadsheet with complete records of when she purchased her medications, cost, and which pharmacy.

Alpha woman, Alice, only relied on her doctor and God for support and states, “Well, he's [her doctor] concerned, you know, you ask questions. You're not afraid to ask questions.” In fact after Alice’s husband passed away, she made her doctor aware of her tight financial situation:

As soon as the insurance stopped ... I went to the doc and I said, doc, I don't have any more insurance, and he tries and says, “Well, can't you go through AHCCCS [Medicaid] or something?” I make too much money.

Alice’s doctor agreed to see her every six months and charge her \$30 for a 30-minute office visit. In addition, he provided samples when she could not afford her medication.

Alpha women expressed they were able to get the information they needed about diabetes and often provided a long list of places they get reliable information about diabetes (e.g. online resources, books, pamphlets, HCPs). Alpha women reported a variety of HCPs had been helpful in providing information to assist in diabetes self-management. Renee recalled a medical assistant, who was particularly helpful,

Before she left, she gave me a book - calorie and carb counting book. It has food named in the book and how many carbs in one serving is and so on and so forth. That was very helpful, and I have two of them as a matter of fact. They're extremely, extremely helpful.

In addition, Alpha women sought a doctor with excellent communication skills. Annie stated succinctly what many Alpha women expected from their physician, “she [physician] would listen to me, which, you know, sometimes doctors don't always listen to you.” Alice elaborated on what she expected from her physician, “You're not afraid to ask questions.” In fact, Jeannie brought a list of questions to her appointments. She

smiled as she related the story, “I had all of my stuff wrote down there.... he [doctor] said, ‘Jeannie, give me that paper’ And he goes down my paper and then he started answering my questions.” Carrie said succinctly, a good doctor visit is one in which “I get all my questions answered.” Carrie further asserted, “I have to be here [doctor’s office], so you’re [physician] not going to play with my healthcare!” Gloria stated what is important to many patients is communication outside of the exam room, “I’ll call and leave a message. He [doctor] calls me back.”

After a discussion of HCP support with women, the researcher prompted, “Who else?” Often baffled Alpha women searched for another answer and several women offered God as an additional support. Alice expressed her strong preference for speaking with God about her diabetes in this way, “Because what human, what can man do to help me out? Nothing. Nothing.” Furthermore, Alice explained,

He'll [God] give me a spiritual understanding, and I think that He will allow me to understand what's happening. He will give you knowledge. God does talk to all of us. They don't realize it, but that little mind in the back of your head - what do you think that is? You? I’m a very religious person, and I go to God, you know, when I have really serious problems.

Some Alpha and Networking women saw God as supportive in their diabetes management and articulated the process of building an intimate relationship with God over time. For example, Vanessa, a Networking woman, spent a great deal of time reconstructing her path to resilience as she recounted a multitude of hardships experienced since childhood. These difficulties included homelessness, poverty, teen pregnancy, an abusive marriage, the death of her beloved father, and incarceration of her sons. It was shortly after her father passed that she was diagnosed with diabetes and she declared:

And all the pain! And I've grown to learn the Word of God — God does not waste pain, so I don't care what the source of pain is that I go through when I do something stupid and bring it on myself or whether it comes from some other. He doesn't waste the pain; He uses it to mature us. And then I used to be such a big crybaby, and it's just so comforting to know that He collects my tears. They're valuable to Him.

Beyond healthcare providers and God, Alpha women did not provide anyone else they perceived as supportive or anyone else they talked with about diabetes. Some Alpha women reported family or friends who went to diabetes education classes with them, but did not see this as supportive of them personally. Rather, the women perceived attending the classes to be supportive of another family member or a way to criticize them later if they did not follow the guidelines suggested at the classes.

Even Alpha women who stated they had friends and family members with diabetes did not talk with them about diabetes. For example, Alice has a sister with diabetes and when asked if she talked with her sister about their shared condition, she was unsure about why she would do that, “We know something about it, so why discuss it? You know what I'm saying? Sometimes it can be depressing.”

Networking Women: “I say that I have diabetes, diabetes doesn't have me”

Diabetes was represented differently by Networking women, “I say that I have diabetes, diabetes doesn't have me, and I don't even really call it diabetes. I tell people I have *di-a-bitties*.” For Monica, this assertion gave her power over a serious illness; she diminished its power by renaming it and laughing about it. Gina chose to look on the bright side of having a diabetes diagnosis, “there's positives in it, I mean you know now why your body's been doing what it's been doing. So all you have to do is just take the actions and you'll get a good result.”

Networking women were adept at connecting with people and constructing a support system that included a wide range of people. Two of these women (Lucy and Marie) were unable to drive, which forced them to find supportive people to meet their practical needs. Women in this group were naturally amiable and optimistic; they talked easily about their struggles with diabetes, but primarily focused on what was going well.

Furthermore, Networking women would elaborate on how their doctor and other HCPs made them feel valued and cared for:

I never had a doctor that made me feel like I wasn't the most important person in there, and the relationships that I've had with my doctors has always — they'll ask me about my children. They'll ask me about my work. It's just they think — I communicate with them. They communicate with me, you know, he [doctor] cares. (Vanessa)

Gina has been seeing the same physician for about fourteen years and reported a good relationship with him. “So he's pretty comfortable, like, you know, really telling me off about how he feels how I'm acting. It bothers me, but it's, like, I know it's because he cares.” At one time, Gina did not have insurance and her doctor tried to help her to be able to continue to take her diabetes medication, “he'll try to give me as many samples as possible.” Now that she has insurance, the cost is not a barrier.

Julia recently began to see the “education doctor,” a diabetes educator, every three months. The diabetes educator helped her understand, “The pills sometimes stop working,” which eased her transition to insulin therapy.

Two Networking women had assistance in obtaining their medication. Vanessa’s husband took on the responsibility of ordering her medication through a mail order

pharmacy. In fact he was so responsible for this task that she felt a bit guilty that she had no idea what the process looked like, “He takes care of everything. It's terrible he takes care of it.”

Networking women felt differently than the Alpha women concerning social support. Gina, a 36-year-old college educated woman reported she has a number of people who were supportive. Her family and sorority sisters all knew about her diabetes and she smiled when recounting their concern and care for her. “So I do a lot of social activities. I think, that's probably the one thing, like, I don't think being diabetic has, like, impacted my social life.” In addition, she felt there was no reason not to talk with people about her diabetes.

Another Networking woman (Marie) who survived a recent six-year prison sentence and living in a homeless shelter while being confined to a wheelchair successfully reached out for social support in her current residence and neighborhood pharmacy.

Finally, Monica, an extremely optimistic 55-year-old woman who lived alone smiled as she told the researcher her oldest son said, “Mom, you're the healthiest diabetic that I know.” In addition, Monica's younger brother, who also has diabetes, moved closer to “make sure that we were okay, and he checks on me.” She goes on to say. “My coworkers, past and present were all aware that I had diabetes.” Moreover, she had close friends that “know that I am diabetic.” She has received support and encouragement from all of these people over the years.

Vanessa provided an example of the Networking woman in the HCP relationship. “I'm one of these people that believes what the doctor says ... and if they say that I need

the pills or the shot or whatever, I take it religiously.” Vanessa is a nurse and listened to her doctors, relying on their expertise. She generally trusted physicians, “doctor's are practicing medicine... they're making their best educated guess that they can make” and acknowledges the patient's role in her healthcare as “it's really the patient's responsibility, the majority of it is to take better care of yourself and don't put all of that on the doctor.”

A caring relationship with their HCP was important to Networking women. Networking woman, Monica, missed the exemplary doctor she had before moving to the Southwest, “God's honest truth. If I had the money, I would fly back.... for my doctor's appointments if I had the money.” She goes on to say that even though he was busy, he took time with her and remembered “stuff that you don't even remember was wrong with you” making her feel he cared. Other Networking women agreed that they wanted their physician to spend adequate time with them; they felt there is no shortcut to comprehensive assessment and building rapport.

Gender: Emerging Typologies for Black Men



Overall, Black men were remarkably different from women in their perception of support in managing their diabetes. When men were asked, “Who helps you with your diabetes?”, they would smile broadly and produce a litany of supporters from HCPs, God, family members both male and female (e.g. uncles, brothers, sons, wives, sisters, daughters, mothers, mothers-in-law), co-workers, and friends. Bret stated with a laugh, “I have a lot of help, a lot of support!” This was in stark contrast to Black Alpha women who were hard pressed to identify support other than HCPs and God.

However, two emerging typologies for Black men included “Warriors” and “Trustees” (Table 9). Warriors were highly educated men; three Warriors had military

backgrounds and two Warriors were currently in management positions at work. These men were advocates for diabetes self-management education as power and sought information that helped them attack the enemy. They attended at least one series of diabetes education classes; many went back for “tune ups” over time.

Trustees were responsible only for information and medical advice given to them; these men were less likely to seek out additional support from family or friends. Moreover, they seldom sought information on diabetes self-management and preferred to rely upon their HCPs to provide necessary information or referrals. Trustees were less assertive in their relationship with their HCPs reporting, “ I do what they [physicians] tell me” which tended toward compliance rather than adherence in the strictest definition.

Table 9. Emerging Typologies for Diabetes Medication Adherent African American Men

Warrior Men		
Characteristics	Representative Quotes	
 <p>Bret Charlie Denzel Ernie Fred Harry Jack</p>	Diabetes is the enemy: “insidious”, “sneaky disease”, “silent killer”	“When the doctor told me about it [diabetes], I mean, I wanted to attack it head-on.”
	In “attack” mode	“I take my pills on time in the morning and the evening. It's a routine to me now.”
	Military and leadership backgrounds	“I may be not able to reverse what happens, so, you know, if I can prevent it, then yeah.”
	Heavy reliance upon routines and regimens	“She [doctor] told me exactly what she wanted me to do, and when she assigned me a diabetic class I went.”
	Primarily college educated	“I've got a list of things that I want to ask her [nurse practitioner] when I go to see her.”
	Broad arsenal of weaponry (HCPs, God, DSME, being proactive, social support, etc.)	“I can't do this alone. I know that there has to be Somebody helping me.”
	Appreciate HCPs who are “direct” and “strict”	“The more you learn about the disease the better off you're going to be.”
		“I have a couple of friends that are supportive that know I have diabetes. I don't try to hide it.”
		“I must do everything regimented.”
Trustee Men		
 <p>Andrew Anthony Gregg</p>	Compliant relationship with HCPs	“When I do what I'm instructed to do [by his physician], it works out.”
	Participate in DSME if doctor recommends it	“She's [doctor] looking out for my best interest.”
	Desire little social support	“Diabetes is just for me, I'll just take care of it.”

Warrior Men: “I wanted to attack it head-on”

Warriors had a unique conceptualization of diabetes. Fred discussed how he characterizes diabetes, “I've always been told it's called a sneaky disease. It's called the quiet disease. It slips up on you before you know it, and I'd say that's a true thing.” Harry concurred and feared complacency in his diabetes care, “You know, to me diabetes is one

of those silent killers.” Bret agreed, “medication you can control it, but it's [diabetes] the silent killer, and you can't control that.” Denzel related an impactful conversation with a friend who was a nurse. He asked her what word she would use to describe diabetes, “And she paused, and she said insidious. And it is. It really is. I just thought that's a very interesting answer. Insidious.” The word resonated with him because “you don't feel any different.”

Many Warriors used language that alluded to “fighting” diabetes; there was a sense of being in competition or at war with the disease. Harry provided context for his adversity to diabetes, “When the doctor told me about it [diabetes], I mean, I wanted to attack it head-on.” Jack talked about the difficulties his aunt and uncle had with complications from diabetes; this motivated him to win the battle, “I go, yeah, I'm going to beat this.” Ernie summarized what many believed about the war on diabetes; “I know that I could have bad results if I don't take my medicine.”

Denzel was a Warrior man who had a long period of time in which he was losing the battle to diabetes. For two years, Denzel was laid off from his job and did not have insurance to assist with buying insulin. Denzel described what was happening when he was losing the battle against diabetes:

I was losing my muscles and my body was feeding off of the fat, because it wasn't getting the nutrition that I was eating because of the diabetes. My muscles — I started losing muscle tissue. My body was feeding off of itself... I didn't feel right. I didn't feel good every day for weeks, for days I didn't feel well.

Denzel has lived with diabetes for 17 years and philosophized about what made him decide to be more engaged in his diabetes management,

I don't know if most people think about this, but I guess there are a lot of people that are planners and there are people who wait for the disaster to hit before they

have prepared for it, and maybe I was the kind of person that was waiting for the disaster to hit. Because for me I felt, well, I didn't feel that much different. I didn't quite understand what diabetes was all about then and even up until now. Well, actually I should say even up until about two years ago, but it was a gradual — I was gradually beginning to learn more and more about it.

For the past two years, Denzel has been able to receive medical care through AHCCCS and reflected upon the consequences of not managing diabetes for many years.

I came to a point where it was a void I'd fallen into, where I had no power. I had no money to maintain care that was needed to the point where I lost a lot in that period. I had a lot of nerve damage that took place. I didn't see or feel it at the time.

Currently, his orientation toward diabetes was one of actively fighting the enemy to maintain his health. "I'm learning a little bit at a time how what this diabetes thing's about. It's insidious. It sneaks up on you. You don't know how bad things are until you start getting to a point of no return."

Warrior men had a wide range of weapons or tools available to fight diabetes. For many men, spirituality was part of their arsenal. When asked about how his relationship with God encouraged him, Harry stated, "It encourages me, because, again, I don't think He's done with me yet, and so even though I have diabetes ... I may be able to touch someone else who has diabetes that I can encourage them that may be going in a different direction." Charlie discussed his view on God's involvement in his health, "Well, you might, you might say that I know that I can't do this alone. I know that there has to be somebody helping me."

Bret saw his relationship with God as a means for mental toughness. "My relationship with Jesus Christ gives me peace that surpasses all understanding. It keeps my heart and my mind." Furthermore, Bret believed joy was imperative when fighting,

“Even when you go through the worst of times and the best of times all at the same time if you have some joy. And I had some joy when I got the news about the diabetes.” That deep abiding joy carried him through managing diabetes even when it was necessary to begin insulin therapy, “I didn't lose my joy, because now I have to stick myself. I have to learn how to do this. And understand it's for my betterment.” Bret asserted his faith “doesn't make it [managing diabetes] any less challenging.” His conviction was that faith in God made handling diabetes easier because “I have a belief system that I won't let go of, and no matter what the situation is, I know that I win in the end.”

In addition to spiritual tools, Warrior men believed in the power of knowledge about diabetes. For example, Bret worked with his HCP to learn more about his disease and stated, “And if they [HCPs] have only given me part of the tools, I'll have something to work with, and I'll educate myself the rest of the way and figure out the rest.” He discussed friends who lost limbs from poor diabetes management and stated with conviction, “I'm not going to do that. I'm not going down that road. If someone gives me the tools to work with, trust me, I'm going to work with the tools.” Bret saw diabetes management as his personal fight for health, “The wars that you do have that are yours, pick your battles, and know that, hey, I may lose the battle, but I'm going to win the war.”

Denzel participated in three DSME classes in three different cities. “And they were all very different. I mean the information was the same, but there were different angles, like different angles at which to attack diabetes.” He advocated for DSME and stated, “I tell people whenever I run into someone who's about to take the class, I say take the class. You will benefit greatly from doing that.”

Warrior men joked about being “nagged” by many people, but when asked how they felt about being nagged, they would say the supporter was showing his or her love and laugh heartily. Furthermore, married Warriors often attributed their ability to take their medication regularly, along with other aspects of diabetes self-management, to their spouse. For example, Jack smiled as he stated, “The main reason I take my medicine.... because she [wife] is always on me about it.” When Denzel’s ex wife reminded him to take his medication, he felt “that was really nice or sweet of her to ask and show that she had some concern.”

Moreover, Jack identified his brother as an important supporter, “He calls me every once in a while to make sure I'm doing what I'm supposed to be doing...he works at the hospital, and he's like, ‘Don't be one of those guys.’ So he helps.”

Warrior men were very open to talking about diabetes with others. Denzel summed up the feelings of many Warrior men, “I didn't see any reason why not to talk about it.” In contrast to Alpha female, Alice, not understanding why she might talk about diabetes with her sister, Harry talked regularly with his brother who has diabetes.

So we talk about that kind of stuff. And he [brother] says, ‘I was on this one medication that worked for me, or did you hear the report about this medication? You may want to talk to your doctor.’ You know, this is the kind of thing him and I talk about.

Bret and his mother-in-law were both diagnosed with diabetes at about the same time and took the same medication. She would call every morning to ask him, “Have you taken your medicine?” Bret replied, “I've taken mine, but have you taken yours?”

Warriors generally agreed upon the qualities common among the doctors with which they had a good relationship. Honest and direct communication from the physician

was highly valued, “I need you [doctor] to tell me what's going on” (Jack). In fact, Bret traveled forty-five minutes for visits with his trusted physician and declared, “The distance is worth the difference.”

Many Warrior men articulated daily rituals and routines that helped them remember to take medication. Bret called himself “anal” and believed routine is imperative for his diabetes management, “So I must do everything regimented. And I don't want to be outside of my routine, because if I'm outside of my routine, now I'm going to forget something.”

Ultimately, Warrior men took personal responsibility for their own health, “Nobody's going to hold your hand. Nobody's going to walk you through this. This is something you must do” (Bret). His optimistic attitude is summed up, “When a person finds out that they have diabetes, it's not the end of the world. It's the beginning of a new life.”

Trustee Men: “I do what they tell me”

Trustees accepted the diagnosis of diabetes and took it seriously. Greg’s mother had a history of diabetes and experienced diabetes-related complications, “For decades prior it [diabetes] was a term as bad as cancer, if not worse, in my mind.” From watching his mother’s health decline, Greg described his characterization of diabetes, “I knew it was a dangerous, treacherous, ugly disease, and I respected it in that way, and when I heard the term diabetes I respected it right away.”

Trustees were generally content to allow the doctor to make health decisions with little interaction from them. For example, Greg, an educated Black man between 40 and 50 years old exemplified a compliant relationship with his physician. Greg described a

poor relationship with the doctor he had been seeing for more than three years, “There's no eye contact. They're either on the computer or on their notepad. Here's a prescription. Here's a refill. On your way.” The office policy was to make appointments with the physician at least four weeks in advance. Greg’s response was, “I stopped making appointments with her.” Instead, he was seeing three different physician assistants (PA) in the same office. In fact, he referred to the physician with disdain as the “prescriber”. In order to obtain a prescription for his diabetes medication, he was forced to see a PA monthly; the office policy does not allow prescriptions to be called in without a doctor visit and Greg never asked if he could see the doctor less often.

Greg discussed a disagreement with his doctor about insulin dosing, “So she took me from 20 units to 14 in one swoop, in one change.” He elaborated, “It [A1C] was good at 20. ‘I'm going to reduce you.’ Isn't that a significant, very significant drop? ‘Yeah. I want to try it. I want to see if it works, how you're doing at 14.’ Okay. I'll follow your orders.” Greg vehemently disagreed with lowering his insulin dosage; he believed that his A1C was in a healthy range and it was a mistake to lower the dose. However, when asked how much insulin he took each night, he took the dose recommended by his physician and declared, “That way it’s on her, not on me!” Greg explained this statement,

They [physicians] will be the first to say, ‘You didn't follow my orders. You didn't follow my instructions. You didn't do X, Y, Z. This is why you're in the position you're in, because you didn't follow doctor's orders. You didn't take the prescription as prescribed. You didn't. So therefore, it's your fault.’

By following the doctor’s orders, if something goes wrong, Greg can say, “I did exactly what you told me to do.”

It was apparent that obeying authority was important to Greg; he could not imagine “challenging” his doctor by discussing the dosage or taking the amount that seemed best to him. Greg continued to obtain healthcare through this office because he does not have “enough time to take care of my personal business.”

Greg had not asked the physician for a prescription that lasts longer than a month, even though he was clearly upset at having to go to the doctor and the pharmacy every month. A year ago, Greg decided he preferred to see the physician assistant in the office and demoted the physician to “prescriber” in light of his unvoiced disagreement with the medication dosing decisions made by the physician. Gregg has not asked questions or challenged medical decisions from any of his physicians, as he felt he would be perceived as “whining” or “complaining.”

Trustee men were not interested in acquiring social support. Andrew summed up the feelings of the other Trustee men, “Diabetes is just for me, I'll just take care of it.” When family or friends reminded them to take medication, it was not particularly bothersome, but Trustee men felt no one else should be concerned. Greg chose not to talk about diabetes with his family because, “I don't have to dump everything on her [wife].” He explained, “So when I'm sick, I have diabetes, diabetic complications, and you don't and never have, it's going to be hard for you to relate so I minimize the harder-to-relate conversations.”

Community Response to Gender Specific Emerging Typologies

Community partners were asked to provide feedback, either individually or in small groups, at various phases of the data analysis. In discussions with African American community members concerning the typologies, the disparity in support for

Alpha women with diabetes was palpable. Typically, African American men were in disbelief; the men were certain all African American women socialized regularly and thought this equated to adequate support. However, African American women had a very different response and would nod in agreement with the notion of low support and feelings of isolation for some Black women with diabetes. The notion of feeling somewhat alone when going through a difficulty of any kind resonated with them. Furthermore, Black women would begin to naturally advocate for their sisters with diabetes, trying to help the African American men to understand the isolation many women feel. One older African American woman who has worked to reduce health disparities for nearly two decades was moved to tears declaring, “I thought we were past that.” Another African American woman who worked in public health shook her head and stated, “Those are my people! That [isolation] is so unhealthy. We know those who have higher social support have reduced depression and better outcomes.” One man who had extensive experience with Black men’s health stated, “It’s like she shuts down resources around her” when speaking about the Alpha woman.

Community partners viewed Networking women as having a healthier attitude towards diabetes management. African American women smiled when reviewing the Networking profile and talked easily about the benefits of creating a support system. One female community partner discussed whether these women were connectors rather than networkers. The difference to her was whether their focus was on connecting to others regardless of personal benefit or whether the networking primarily benefitted their own health and well-being. She decided that Networking women were creating an environment to support their own health and as an aside, improving the lives of others.

While most community partner African American women easily pictured Trustee men, many were unfamiliar with Warrior men. After consideration, the women were able to picture these men in their community stating that they do not work much with adherent clients; therefore, Warrior men were not as common in their practice situations. However, both male and female community partners knew Black men who, in general, “attacked” problems and depicted this approach to adversity.

Community partners more easily understood Trustee men. Community partners related to the sense of the doctor as more knowledgeable and, therefore more trusted to make medical decisions than the patient. However, the concern was whether all physicians deserved that high level of trust. Community members questioned turning over important health decisions and well-being to one person. Moreover, several community partners asked about the race of the physicians. When told that participants primarily had white HCPs and did not express a preference for an African American HCP, one woman stated, “In Arizona, there aren’t many Black doctors, so they don’t really have a choice.” In fact, if participants had a preference, they were more likely to choose a HCP of the same sex.

A community partner with extensive experience in Black men’s health issues suggested the Trustee men might be empowered by having “talking points” to discuss with their physicians. He was further troubled by the short time period of doctor appointments and asked, “Is this enough time to get information?” He believed physicians must understand the power differential and the potential to influence Trustee men.

Perception of stigma and acceptance of the diabetes diagnosis were common among all participants. Certainly acceptance of the diabetes diagnosis was instrumental in diabetes medication adherence and precludes initiation of consistently taking medication. In order to engage in the laborious process of obtaining and taking medication as agreed upon between the HCP and patient, he or she must see a need for the medication.

However, conceptualization of diabetes and orientation toward self-management differed according to gender and other demographic factors that clustered within four emerging typologies. Furthermore, support from others, including HCPs, differed according to gender and typology. Thus, the challenges experienced for each person were different; the manner in which each person engaged in the process of medication adherence and solved the challenges inherent in this process were unique as well. The value in exploring this process of medication adherence is in the differentiation of the steps and, therefore, the potential pitfalls, at each phase of the process. The resilient people in this research study were not daunted by the challenges; they found creative ways to overcome adversity and risk at each stage.

The Process of Medication Adherence Model

The data revealed a multi-step process of medication adherence with potential obstacles at each step that may have to be overcome (Figure 11). Participants described the process of acquiring their prescriptions and the strategies they used to overcome common hurdles in remaining adherent. Each point represents a necessary step in the process of medication adherence. Moreover, the patient must successfully navigate through the process to achieve consistent medication adherence. There is potential for

adversity and risk at each stage of the process where patients must have the assets and competence to overcome any barriers to be able to consistently take their diabetes medication.

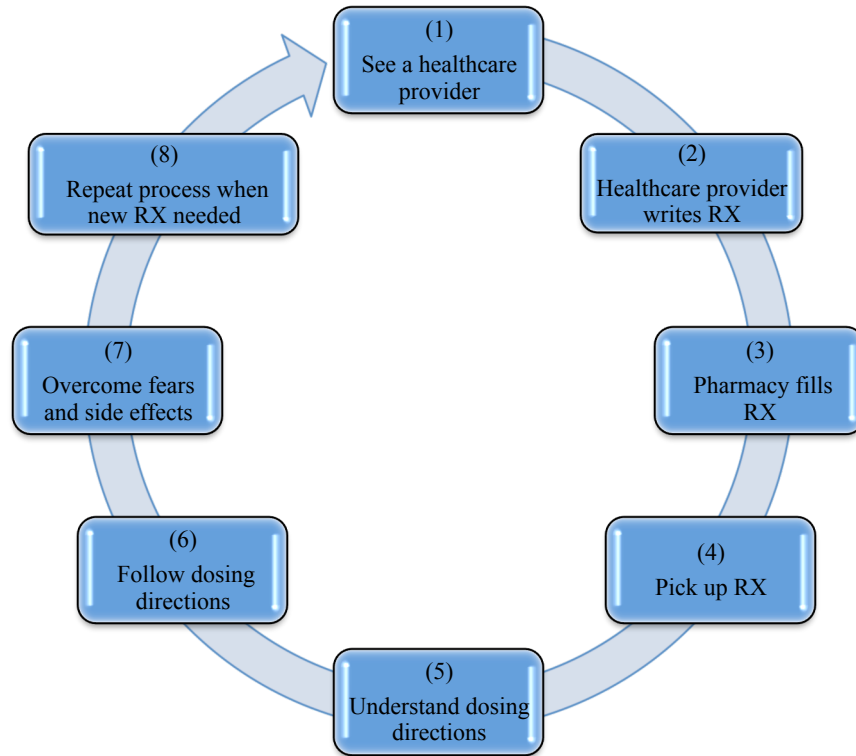


Figure 11. The Process of Medication Adherence

Step 1: See a Healthcare Provider

The initial step in diabetes medication adherence involves seeing a healthcare provider to obtain an accurate diagnosis and develop a plan for treatment. Participants in this study discussed various roadblocks to seeing a healthcare provider including difficulty in making an appointment in a timely manner, transportation, work-related obstacles, office policies, and paying for the visit. Their strategies for successfully overcoming barriers may be helpful to others who are struggling with this initial step.

Come to the appointment. A few of the participants did not drive (Marie, Lucy, and Andrew); thus, finding reliable transportation to appointments could be a problem from time to time. Marie and Andrew had AHCCCS coverage, which included rides to medical appointments, but not to the pharmacy. This was a great advantage to both of them and they were very satisfied with this benefit. Lucy had Medicare coverage and relied on public transportation and her daughters for transportation to her appointments. All three participants were able to get to their doctor appointments with consistency.

Other participants were concerned about missing work for an appointment and those who were currently employed scheduled their appointments around their work schedule. For example, Monica routinely asked for the first appointment of the day with her physician. In order to be able to get this coveted time slot, she built rapport with the office staff, and made her follow up appointments at the end of her current visit. This strategy required prioritizing her doctor appointments, but allowed her to limit missed work time.

Pay for the visit. With the exception of Alice who did not have insurance coverage to assist with medical costs, participants did not feel copays for doctor visits were burdensome. Alice was able to be open with her physician about her financial situation and brokered a reasonable compromise in payment of \$30 for her regular office visits.

Step 2: Healthcare Provider Writes Prescription

Prepare for the visit. Participants generally felt that if they provided good information to their physician, HCPs would make better decisions. It was important to know how the current medication was working in order to know if any changes should be

made. Toward this end, participants had a multitude of strategies for getting the most from the short time they had to meet with their HCP (Table 10).

Table 10. Participant Strategies for Preparing for a Doctor Visit

-
- Write down questions for HCP ahead of time
 - Prioritize those questions
 - Tell the doctor if you need a refill on a prescription
 - Bring a completed blood sugar log book
 - Provide a food diary
 - Bring in bottles of all prescription medications
 - Keep a brief medical history in a purse or wallet
 - Keep a list of current prescription medication in a purse or wallet
 - Get blood drawn 3-4 days ahead of time
-

Seventy-seven year old Jeannie shared her strategies to get what she needed from her doctor visit,

I write down my questions before I go [to the doctor]. Before I started doing that, I would go in and, you know, sometimes, my talking sometimes gets kind of spacey like. I'm still trying to come up with that next question, and they will be gone.

Renee concurred with this strategy, “I did the list with my primary care and I find that she paid more attention to me.” Renee found a list was particularly helpful when she could not communicate her thoughts clearly, “I just handed it to her [doctor] and let her see it, and she did address what I had.” Charlie used the same strategy with success, “I've got a list of things that I want to ask her [doctor] when I go to see her.” Carrie went a step further and prioritized her three most pressing topics for conversation with her HCP, “If you can't deal with the rest of them, I'll come back, but don't rush me.”

Annie was a meticulous record keeper and provided an updated copy of her 3-page medical history to her physician to revise or add to on the day of the visit. “So every time I go I just give them [doctor's office staff] an updated copy [medical history], and

then I keep one in my wallet just in case of an emergency. Everything is there that they need to know.” Many participants brought a logbook with blood sugar readings and a food diary to doctor visits.

While many participants kept an updated list of prescription medication with them, Carrie found updating a list of medications to be unreliable for her because prescription medications changed so often. She saw a number of specialists and each one may prescribe a medication to treat or prevent conditions. Instead, she brought a bag of current medications with her wherever she went to be certain all doctors were aware of all prescription medications (Figure 12).



Figure 12. Carrie’s Medication and Supplies

Several participants expressed they wanted to review current lab work with their HCP at each visit; therefore, they did what Harry did, “I get my blood drawn three or four days before [doctor appointment].”

Participants believed all of this prior preparation allowed the patient and physician to discuss the current treatment and decide what kind of medication is needed and whether any changes to dosage or strength needed to be made. After the information

is synthesized, the HCP wrote a prescription and handed it to the patient or faxed/called one in to the pharmacy. This could be either a mail order or local pharmacy, depending upon the preference of the patient and the insurance provision.

Writing the prescription correctly. Some participants discussed the mismatch between the prescription and the number of doses of the medication needed for the time period. For example, Gina discussed a problem with having enough Victoza, “I think sometimes it comes down to, like, how the doctor writes the scripts.” She elaborated, “there's the instructions, and then there is the quantity.” She discussed that she had instructions on how much and how often to take the medication, but not enough of the medication to follow the written directions. Her solution was, “So I have to read the prescription to see if it matches.” This way she could catch any errors before she left the doctor’s office.

Mail order. For mail order pharmacy users, the process from the HCP calling in the prescription to having it delivered was very simple. For example, Jack set an alarm on his cell phone to remind him every three months to order his medication, which he received by mail order. Jack stated the simplicity of the mail order process as, “Just call the doctor, he sends the order [to the mail order pharmacy]. And then he will send it off, and they'll [mail order pharmacy] send me some more.” Jack added that it took two to three weeks for the refill process to be completed, “because then they've got to call me and verify that you want it.” This process took minimal effort on the part of the patient. Ernie also enjoyed the simplicity of using a mail order pharmacy, “you just put in your [prescription] number, and they tell you you'll get it within seven to ten days, and they're usually pretty punctual.”

Step 3: Pharmacy Fills Prescription

HCP fails to call in prescription. While the hand off from the doctor to the pharmacy could pose problems, few participants expressed difficulty with the pharmacy receiving the prescription. However, this may be because most preferred to take the written prescription directly to the pharmacy rather than rely upon the physician's office. Those who used a mail order pharmacy could not recall a time when the prescription was not received by their pharmacy.

Patient takes prescription to pharmacy. Many participants chose a pharmacy in their neighborhood or close to their place of employment. Several participants used a pharmacy within a grocery chain. This enabled them to run other errands while waiting for the prescription to be filled. Transportation challenges were minimized with this strategy; however, those who relied on public transportation often found it difficult to get to the pharmacy to drop off and pick up prescriptions in a timely manner.

Those who utilized public transportation solved this problem. Marie chose a pharmacy within two blocks of her home and used her wheelchair to travel to and from several times a month. Lucy had her physician call in the prescription instead of making the trip to drop off the prescription. Andrew used public transportation and waited for the pharmacist to fill the prescription rather than make another trip.

Step 4: Pick Up Prescription

Monthly task. Participants did not expressed feeling burdened by picking up their prescriptions from the pharmacy. Lucy, who does not drive, called the pharmacy every month to order her medications and then informed one of her two adult daughters that they have three days to pick up the prescription and deliver it to her house before she ran

out of medication. For many local pharmacy users, picking up their prescriptions had become part of their monthly tasks. Ernie reordered and picked up his insulin, “Usually when I'm down to the last 3 cartridges I will call them [pharmacy].”

Jeannie described her process for knowing when it is time to get her medication from the pharmacy, “And when I get down, I fill that pillbox up, and I probably have 3 or 4 more days left, and that's when I think I should order.” If she did not follow her self-imposed rule, she realized, “I'm not going to have any medication, so that's when I take myself to the pharmacy and sit there until they refill it.” She viewed having to wait 20-30 minutes for the refill as “punishment” for not ordering medication when she knew she was low.

Pharmacy reminders. Many participants spoke about pharmacy-based reminders to get refills of their medication. These reminders came in the form of automated phone calls, text messages, or emails. Renee described her pharmacy's refill reminder, “They [pharmacy] automatically fill it [prescription] every month and then they let me know when it's ready.”

Correcting prescription errors. Renee reported a number of times when her pharmacy did not provide the proper drug or left out one of her prescriptions. She had a strategy for making certain she had everything she needed before she left the pharmacy, “well they [pharmacy personnel] bring it to me, and before they ring it up I go and check my list against what they have.” Renee kept her list on her cell phone to ensure it is always with her.

Gina had a problem with a prescription for her glucometer test strips and had to speak with the pharmacist about correcting the number of strips she received. She

believed correcting this error would have been much more complicated if she had a mail order pharmacy, “Just talking to the pharmacist is way easier than talking to someone over the phone at a mail order pharmacy to get the whole thing figured out.”

Paying for the prescription. Most participants had insurance and were able to cover the cost of co-pays. Greg asserted a frustration shared by many participants, “And then when my insurance changes, the pharmacy changes.” As a result of this change of insurance and concurrently a change in pharmacy, the loss of the relationship with their pharmacist and familiarity of the routine that was working were challenges to overcome.

Furthermore, many informants told stories about challenges with cost in the past that affected their ability to be adherent to their medication. Moreover, a few discussed the challenges of falling into the “donut hole” with Medicare when prescription payments were the sole responsibility of the patient.

Alice had no insurance and paid out of pocket costs of approximately \$200 a month for her diabetes medication and supplies. She went without other things (e.g. new clothes, meat) in order to pay for her medication. “That's my life! My life is my health, really. People don't realize that until you get sick. You can't even put a price on health. You really can't. I don't know how people think they can, but you can't.”

Jeannie decided that she would delay retirement until she was eligible for Medicare; she knew she could not afford health insurance and would not be able to pay for her diabetes care without insurance. Jeannie’s husband falls into the donut hole around August of each year and she declared, “We run for the border.” She clarified, “We go into Mexico. More affordable.”

Renee was unable to afford her insulin when she first came to Arizona. Her strategy was “I'm going to take a little less of that [insulin].” She soon realized that she needed the full dose of her insulin and was able to obtain Medicare coverage as a part of her disability package to assist with the cost. Vanessa stated when finances were tight, she always prioritized insulin, but would sometimes have a week when she could not refill her OHAs.

When Denzel could not afford more syringes, he reused them to save money.

And so I had maybe five needles left or something, and I had two weeks — I had two bottles of insulin left. Before I was able to get the money to buy the syringes I had to double up, triple up on these syringes.

Moreover, he recalled times when he could not find the few dollars necessary for the co-pays for his medication and it would be quite stressful.

Charlie discussed the difference in having Veteran's Administration (VA) benefits. “Since I've got the VA, there's no cost, but prior to getting the VA, it was, it was, it was a burden. It was a burden.” He encouraged those who are eligible for VA benefits to use it, “If a person is VA eligible, he should seek the medical supply from the VA, because it would save him a tremendous amount of money.”

Even though Annie had insurance, she paid \$300 to \$400 a month for her diabetes medication and supplies. Annie decided to talk with her doctor about her inability to afford the medication she was prescribed. She called the pharmacy because “the last time I had it filled for 90 days it was \$70. Now it's \$2100” and the pharmacy responded, “It's because you're in the donut hole.” Annie explained the “donut hole” as,

Well, you have a limited amount of money to cover your drugs for the year and if you use them all up in the first 6 months then you in the donut hole, so you're responsible from then on. That means you pay full price for the medicines.

Annie reaches the donut hole in May of each year and had to stop taking medication for a time due to cost. To remain adherent to her diabetes medication, she obtained samples from her physician when she could not afford her medication.

Step 5: Understanding Dosing Directions

Confusion about taking diabetes medication. Sometimes directions for using insulin were extremely vague. Julia's doctor gave her rapid-acting insulin with these instructions, "He said, here, just take a little bit of it [insulin]. Just be careful with it." Subsequently, Julia had some scary hypoglycemic episodes and stopped taking rapid-acting insulin. Ernie's endocrinologist was similarly unclear about how much insulin to take after Ernie reported persistent high blood sugar after initiating insulin therapy, "He [endocrinologist] said, 'just try using more insulin.'" Ernie researched diabetes self-management for himself and stated, "I just became very, very strict about watching what I ate, exercising and so it's exercise and diet, and then I got my number [blood sugar] from 400 down to 100."

Participants expressed times of confusion over what the directions indicated and what they were told by their HCPs. For example, Annie told about a time in which her doctor was helping her to increase her long-acting insulin safely, "They [physician] had me taking Levemir [long-acting insulin], and they kept telling me just keep increasing it every 4 days by 2, every 2 days I think it is by 4 points until I got it under 140 in the morning?"

Several participants were unsure about whether insulin needed to be refrigerated or not. Jack was confused about what he was told, "It says don't refrigerate it. In the

refrigerator to keep it, but once you — before you use it has to be room temperature or something like that.” Gloria experienced conflicting information about the refrigeration of insulin from her HCPs, “So with the Humalog...what my endocrinologist told me was the Humalog could be at room temperature.” However, when she talked with the pharmacist, “Pharmacist says, ‘No. We give it to you out of the refrigerator, why wouldn't you keep it chilled?’” She sighed in frustration.

A number of participants took time to read the information that came with their medication before they left the pharmacy. This strategy helped them to make certain they understood what to do when they got home. Most participants considered the written directions to be the definitive resource for resolving conflicting instructions.

Step 6: Follow Dosing Directions

Remembering to take medication. Setting up the home environment for success was integral to taking prescription diabetes medication on time and consistently. This included keeping medication and supplies in a central spot and connecting taking medication to other established habits.

Many participants kept their medication in a central location (e.g. bedside, bathroom, kitchen counter) as a matter of convenience. Julia took her medication first thing in the morning and before bedtime. She had a system, “So it's [medication] by my bed, and I have, this little thing with my insulin and my needles and my pills is in this little green basket, and that's what I use to remind me to take it.” Furthermore, she kept bottled water and extra insulin in a small refrigerator by her bed.

Lucy kept a zippered lunch bag of her medication and supplies on the kitchen table with her dosing instructions for insulin stapled to the lid (Figure 13). This helped

her to remember to test her blood sugar and take her medications regularly. Furthermore, if she went on a trip, she just zipped the bag closed and packed it in her suitcase. Denzel had a similar system. He kept all of his “tools of the trade” (e.g. syringes, lancets, glucometer, pillboxes) in a cloth tote bag in the dining room. In addition, he used pillboxes to organize his medication. Weekly, he filled two sets of pillboxes; one was for morning medicine and one was for medication to be taken in the evening.



Figure 13. Lucy’s Bag of Medications and Supplies

Charlie developed an innovative system for knowing which medication to take in the morning and which to take in the evening.

I've got a medicine cabinet. It's got three shelves in it, one, two, three, and I take, let's see, four shelves, four shelves in it, three partitions, four shelves. I've got medicine I take in the daytime. Okay, now I say the medicine I that I take in the daytime, that's medicine that's standing up. That's when I'm standing up. I'm upright. I got them one, two, three standing up from top to bottom this-a-way. Now the medicine I take at night is when I'm lying down. Now they run on the shelf this way (on their side). I know it's crazy, but it works for me.

Furthermore, many participants connected taking their medication with another activity that was already a part of their established daily routine. For example, when Ernie was first trying to remember to take his diabetes medication,

I started putting it in those pill cases, so I just leave a pill case on the counter, so when you come in in the morning, and you want to go in the refrigerator the pill case is right there. Like, oh yeah, that's my medicine I need to take.

Others, like Charlie, naturally connected taking their medication to meal times, “twice a day and before breakfast and before dinner.” Most participants were keenly aware of the time to take their medication. Therefore, the clock or a television show became a reminder to them. Harry explains, “It's just that I kind of know at 9 o'clock I want to do it [take diabetes medication], so when I look over [at the clock], I say, oh yeah. It's kind of become a regimen for me.”

Those that had a longer history of taking diabetes medication felt it was just a part of their everyday routine. In addition to his shot of insulin at bedtime, Fred stated, “I've been doing it [taking diabetes medication] for years at the same dosage, too. I take it in the morning. I take it in the evening. I take about eight pills in the morning and six pills in the evening.”

Having medication with you. While Carrie had a plastic bag with all of her medication that she carried in her tote bag everywhere she went (Figure 12), most participants took time to think through their daily schedule and decided if they needed to bring their medication with them or not. For example, Gina had a system,

I figured out this is the best direction for me. I used to carry a big pill bottle... with lots of pills in it. Now I only carry the dose for the day. Every morning, I just cut two pills in half and have that with me.

If insulin was needed while away from home, most felt comfortable not refrigerating it as long as they kept the insulin in a temperate environment (e.g. desk drawer, purse, shirt pocket). Pills were often tucked into a purse, pocket, backpack, or briefcase in their original bottle. Charlie got a little help from his wife, “If I'm going out

to a restaurant, won't eat at home, I'll put my insulin in a pen and put it in my wife's purse since I don't have a purse." Some people habitually carried a small pillbox or sandwich bag with a few pills. On occasion, participants were out and unable to take their medication on time; most were comfortable with taking the missed dose as soon as they returned home, "better late than never."

Step 7: Overcome Fears of Taking Medication and Side Effects

Fear of needles. Not all participants had an aversion to needles. Marie stated, "Well, shots don't bother me. I'm not scary of shots and stuff like that, it just something I didn't do it so much." Vanessa was motivated to feel better, "I'm not afraid of shots. I just wanted to feel better. I was willing to take the insulin, because I wanted it [blood sugar] to be controlled better." Vanessa later discussed her experience with immunizations, injection pain medication for dental procedures, and labor stating, "I've grown up to love shots. To take away the pain, because I have a low pain threshold, so taking insulin shots didn't bother me." When she had gestational diabetes, Monica was not troubled by the thought of taking insulin injections,

When I first had to take insulin, I was protecting me and my baby. I was carrying my baby, so that didn't bother me. I saw that the insulin helped my father. I saw that the insulin helped my sister. I was never resistant to taking insulin, because I saw the benefits.

When asked about taking insulin shots, Denzel shook his head, "The needle, the syringe, the needle I use for diabetes? No. That's not a problem. Most of the time you don't, you don't feel the sting, if there is a sting."

However, Harry's feelings about needles were representative of many participants. "We are not friends. At all." He was able to overcome his fear of taking

shots by thinking about what could happen if he did not take his insulin. “And so, yeah, and then some folks that I know that they have had, you know, amputations because of diabetes and things like that.” Some participants expressed a preference for an insulin pen as opposed to the syringe and vial method of administering insulin. Harry was surprised that insulin injections with a pen were not as painful as he thought, “...the pen is just, to me, it's a little different... you can do it yourself, and it's just, boom.” While Bret was not happy about “sticking” himself, he was a paramedic at one point in his life and needed to inject patients on occasion, “It's no problem for me to stick somebody, It's not going to hurt me, I mean, this is something to help them live.” He applied this reasoning to his own situation,

So I had to get that wrapped around my mind, that this was going to help me. It was going to be faster. It would be easier at some point. For when I get over my fear of having to poke myself with a needle that I don't feel comfortable with for my own self.

He summed up his experience with injections, “It's not as bad as you think it is.”

Alice discussed her feelings about having to give herself the first insulin injection, “It was frightening. I just cried and cried and cried, and I'd even ask my husband help me out. Give me my shot. He said, ‘Are you kidding?’ He's afraid of needles too. Anyway, so I had to learn.”

Gloria shuddered when she stated, “And what I finally found out, too, about the shots, it just, it just hurt.” Andrew was similarly succinct in his thoughts about insulin therapy, “I don't like needles. I didn't like it too much, but I had to do it.” When asked why he had to take insulin, he stated simply, “Because it [uncontrolled diabetes] can cause you know, coma, diabetic coma, paralyzed, you can get a stroke or whatever.

Different things can happen that's very serious.” His fear of long-term complications outweighed his fear of the short-term discomfort of the injection.

Some participants were periodically overwhelmed by their fear of needles and would ask a loved one to help out. Julia relied upon her boyfriend to administer the injection during these times, “Because sometimes when I just don't want to do it. Sometimes I don't want to stick myself... I say, here honey, stick me.”

Carrie gave herself insulin injections for about five years and still struggles,

Even right now to this day, and it's been five years, almost five years. And I alternate points, but I'm still, like, every time I'm hesitant. I'm like, oh my God, I hate doing this. Why do I have to do this? Okay. Take a deep breath. All right. And go. Okay. Wait. Okay. I'll do it in a minute. Wait, wait, wait.

Carrie believed her athletic training helped her to do many of the tasks necessary for diabetes management. The discipline and self-regulation she learned as a young athlete prepared her to do things that are beneficial, but are not easy.

After several years of increasing OHAs and increased difficulty controlling blood sugar for more than about six months, Greg started on insulin therapy. “The transition to insulin went well. Besides the shots. I have a problem with the shots in my stomach. Still to this day.” He overcame his distress of giving himself insulin injections because he felt so much better, “But as far as how I felt physically, the insulin was a huge improvement. A huge improvement.” In spite of his disdain for giving himself injections, Greg recommended starting insulin therapy, if needed, “The doctor, if they know anything about treating diabetes, they say, ‘you're ready for insulin, or you're an excellent candidate for insulin.’ Do it. That would be validated.”

Anthony was particularly fearful of taking insulin. He watched both of his parents take insulin injections for years and remembered hoping he would never need insulin. “I knew that they [parents] had to do it [take insulin shots], you know, because they wanted to live a long time. My mother died at 75, and my father died at 79.” Anthony attributed their long life to “They did what they supposed to be doing.”

Gina discussed her concern about “shot etiquette” and the proper way and place to administer injections when around others, “No one ever tells you about shot etiquette, like, do you do it at the table? Do you do it at your desk, you know?” Moreover she was unsure about the proprieties of glucose testing in public, “should you poke your finger around people or should you not do it around people, you know?” When asked about her practices concerning shot etiquette, she stated, “they're probably going to freak out about, like, blood than anything else, you know what I mean?” She just made sure she had an alcohol wipe handy to clean up quickly after blood sugar testing. For administering shots, she decided, “So I can do it through my clothes, which is, like, no big deal.”

Weight gain from diabetes medication. Sixty-four year old Gloria articulated her struggle with a common concern for participants about insulin therapy,

The issue for me is that diabetes — insulin is a growth hormone, and I'm like do I need to be bigger? I don't think so. But do I want to live? Yes. I want to live to 105 and die in childbirth. I am not going to be able to do that until I get the diabetes under control.

Monica also believed that insulin contributed to weight gain, “I too struggle with the big gut. I can't stand it! I believe that it's there because of the insulin.” However, Monica discussed other factors involved with her size. Ultimately, she valued her health and believed taking insulin will keep her healthy even if she carries extra weight.

Greg gained “overall, 45-50 pounds” as a side effect from one OHA. He accommodated the weight gain by having his clothing altered. However, he continued to be concerned about the weight gain because it made the diabetes “not only harder to control, but it's worse for managing diabetes overall.” His physician told him, “You need to start exercising and losing weight.” His doctor added another medication used to treat high cholesterol, which had the added side effect of chronic muscle pain. Greg related the triple barrier to working out as, “So fatigue, muscle pain and weight gain.” Eventually, while on the OHA, Greg was able to lose 40 pounds through diet and exercise. His A1C improved for about six months and then began to increase.

Gastrointestinal problems. Carrie’s pharmacist was her primary source of support and information about diabetes medication.

When I first got diagnosed with diabetes, I was asking him [pharmacist] about the metformin, and he was telling me, ‘Well some people can tolerate it and some people can't. And I couldn't for a long time. It made me so sick to my stomach. She had difficulty with eating and taking her insulin, “If I took it [metformin], I couldn't eat. Then when I didn't eat I couldn't take my insulin, but then I had to take my insulin even if I didn't eat, which made me, oh God.” Carrie sought support from her trusted pharmacist and he told her, “You have diabetes. This is what it's [metformin] going to do to you, I mean, but you have to take it. There's nothing else you can do.” Carrie pushed through and the side effects dissipated.

Julia talked about unwanted side effects from her diabetes pills, “It [Glucophage] started giving me diarrhea, and they say, well, you've got to keep continuing to take it.” Julia talked with her doctor and her doctor encouraged her to stay on Glucophage. “So I'd been taking it [Glucophage] all these years, and all of a sudden, every blue moon I get

diarrhea. Sometimes — one time I pooped on myself.” She continued to be plagued by diarrhea, “It would go away and come back. Yeah. And so she [doctor] took me off, and I haven't — I'm good now.”

Having a discussion with a trusted HCP about unwanted side effects from medication either encouraged the patient to persevere or to decide on an alternative course of treatment. Gina was taking an OHA that caused her to have diarrhea; she spoke with her doctor about the problem and “he ended up switching me to Januvia, Januvia-metformin combo. And that helped.”

Higher blood sugar. Often when patients initiated insulin therapy, HCPs prescribed a lower dose than may be therapeutic to prevent hypoglycemia. Annie was not aware of this practice and she was not sure that insulin was helping her to gain better control of her blood sugar, “But then she [physician] was the one who put me on the Levemir [long-acting insulin] and stuff, and that's when I thought that my blood sugar started to go up rather than down.” Annie pointed out entries in her logbook “Because if you notice they started going up.” Annie persisted and the physician adjusted her daily dose of insulin incrementally; she improved her blood sugar control over time.

Ernie had a similar experience, “I took the insulin, went back to see him [endocrinologist] for a follow up in 2 weeks. My numbers were 450!” In addition to working with his endocrinologist to adjust the insulin dosage, Ernie engaged in learning about insulin therapy through the Internet and diabetes education classes to gain better control of his blood sugar.

Hypoglycemia. Some participants discussed severe hypoglycemic episodes from having too much insulin in their system. Marie was hospitalized several times due to

severe hypoglycemia. Charlie related a time when he took his insulin and went to get sandwiches, “I just blacked out somewhere between picking up lunch and getting home.” Charlie now checks his blood sugar before driving and keeps “something really sweet that I can get into me quickly to make sure that it doesn't reach that point where it's [blood sugar] down in the 40s.” Furthermore, Charlie checks his blood sugar before bedtime and eats a snack if necessary, “a couple graham crackers or maybe half a cup of glass of milk or something like that to make sure that I don't run down low during the night.”

Participants who discussed episodes of severe hypoglycemia reported taking preventative measures to avoid this problem in the future. Among those strategies were eating a snack, testing blood sugar more often, becoming aware of the symptoms preceding hypoglycemic episodes, and waiting to take insulin until food is available.

Step 8: Repeat Process When New Prescription or Refill is Needed

Most participants had refills on their prescriptions for at least three months and used this as a reminder to make an appointment with their physician within the next month. “And then when I get down to that last refill, that tells me when it's time to go to the doctor” (Bret).

A retail pharmacy or mail order pharmacy may solicit prescription renewal from the physician as a service to the patient. However, some participants' HCPs would not refill a prescription without seeing the patient every month; these patients felt unduly burdened by monthly doctor appointments in order to remain consistent with their diabetes medication.

Summary of Findings

Important individual and broader environmental mechanisms are associated with adherence to diabetes medication(s) for African Americans with Type 2 diabetes. Both internal and external factors that enable African Americans with diabetes to adhere to diabetes medication were identified. Furthermore, these resilient participants were able to go beyond medication adherence to develop a broader understanding of the disease and how to manage it.

Many participants and community members were well aware of the stigmatization in the African American community associated with having diabetes. While some informants made a conscious decision to not share their diagnosis with others as a means of avoiding judgment and unwanted attention, many participants were open about their diagnosis. Those who were more open believed there was nothing to be ashamed about and thought discussion of diabetes allowed them to be more informed and created a safer environment. Their motivation for sharing with family members was twofold; they understood that genetics played a part in diabetes and wanted to be a positive example for their family.

Moreover, participants accepted the diagnosis of diabetes and understood the potential ramifications of not engaging in adequate diabetes self-management, including medication adherence. Participants often told stories about loved ones who suffered dire consequences as a result of poor diabetes management, which provided caution about the need to be vigilant about their own diabetes management. In addition, informants believed taking care of diabetes now would allow them to be healthier in the long term.

The healthcare team included physicians and a variety of other members (e.g. diabetes educators, nutritionists, physician assistants). However, one of the more salient members of the healthcare team was the pharmacist. The majority of participants obtained their prescription medication through a local pharmacy as opposed to through mail order. Many participants had tremendous respect and trust in their neighborhood pharmacist. The reasons for this choice were as follows: 1) they get refill reminders; 2) they have a beneficial professional relationship with their pharmacist; 3) it is part of their routine; 4) problem solving is easier in person; and 5) they could obtain reliable diabetes information. Those who chose a mail order pharmacy cited the convenience and believed the simplicity of this process helped them to more easily obtain diabetes medication.

Four emerging gendered typologies were noted: 1) Alpha women; 2) Networking women; 3) Warrior men; and 4) Trustee men. It is important to remember that all of these typologies were associated with diabetes medication adherence; there is not one way to be successful at taking diabetes medication.

Alpha females were more likely to be keenly aware of stigmatization; therefore, they were less likely to talk with others about their diabetes. However, they were interested in learning about diabetes management and engaged in diabetes self-management education in their own and in groups. Alpha women were strong independent women who viewed diabetes as a weakness or vulnerability. They had high expectations for their HCPs and were highly assertive in their relationship with HCPs. These women were likely to discuss their relationship with God as personal and supportive, believing God provided guidance and help when they need it.

Networking women acknowledged the stigma related to diabetes, but were open

about talking about diabetes with others because they valued the support of family, friends and co-workers in addition to their HCPs and God. Their support network was ever-increasing and judgment from others was of little concern to them. Their optimistic orientation toward caring for their diabetes transferred to their relationship with their HCPs; these women generally felt cared for by their healthcare team. For many Networking women, God was a partner in life and that included diabetes management.

Warrior men were educated men who viewed diabetes as the enemy; they were at war and welcomed any addition to their arsenal. Therefore, these men had a large support system, which included their healthcare team, family, friends, co-workers, educational resources, and a relationship with God. Knowledge was power and these men often went to diabetes education classes more than once after diagnosis. Warrior men appreciated a HCP who was direct and clear about what needed to be done to win the fight against diabetes. Warrior men favored a consistent regimen when engaging in diabetes self-management; they were extremely disciplined, rarely wavering from prescribed routines.

Trustee men described a compliant relationship with HCPs, believing the doctor knows best. These men would do whatever the HCP recommended without question, even if they disagreed with the treatment plan. They seldom engaged in discussions with HCPs or others about diabetes management. They did not want much social support and quietly took care of themselves.

The process of medication adherence model aids in understanding internal and external factors that enable African Americans with diabetes to engage in medication adherence. Furthermore, these resilient participants were able to overcome common barriers and pitfalls to achieve diabetes medication adherence on a consistent basis.

Participants often had routines to support diabetes medication adherence, which included preparation for HCP appointments, convenience of pharmacy location and relationship with pharmacist, rituals around taking medication, and strategies for overcoming fears and side effects. These resilient people were able to creatively problem solve points of potential adversity and develop solutions that allowed them to persevere and consistently take their diabetes medication.

Chapter 5

DISCUSSION

This study explored the broad question, “What mechanisms are associated with adherence to diabetes medication(s), including insulin, for African Americans?” More specifically, this research project had two primary aims:

Aim 1: To explore what individual and broader environmental mechanisms are associated with adherence to diabetes medication(s) for adult African Americans with Type 2 diabetes.

Aim 2: To identify internal and external factors that enable African Americans with diabetes to go beyond adherence and to develop a broader understanding of the disease and how to manage it.

Resiliency is an important mechanism of protection characterized as an adaptive response to stressful circumstances (Billingsley & Morrison-Rodriguez, 2007; Hill, 2007; Rutter, 1987). Resnicow and Page (2008) suggest, “Change is usually conceptualized as rational and a deterministic process in which individuals obtain information, consider pros and cons, make a behavioral decision, and then plan a course of action” (p. 1382). Many assume this process is under the conscious control of the person making the change; however, this may not necessarily be the case. Internal and external forces influence people without their conscious assent. Resnicow and Page (2008) further assert, “It is not so much a planned decision, but something that arrives beyond cognition” (p. 1382). Moreover, Rutter and Sroufe (2000) suggest, “mechanisms involved in causation might entail dynamic processes operating over time, that indirect chain effects might often be present, and that there might be several different routes to the same outcome”

(p. 268). Certainly there is no one-size-fits-all formula to diabetes medication adherence; participants each shared their own pathway to adherence. Thus, the value of this research is in increasing our awareness of the shared processes involved in diabetes medication adherence and pursuing a deeper understanding of examining how participants arrived at the decision(s) required to be adherent.

The themes elicited from this study: 1) illness perception and empowerment; 2) salient formal and informal support; and 3) strategies for navigating the process of medication adherence suggest a number of mechanisms that were associated with medication adherence and can be extended to others. The participants in this study were all on insulin and adherent with their medication as measured by the SMAQ. In short, their acceptance of the diabetes diagnosis, beliefs about diabetes, self-efficacy, personal locus of control, and the importance of taking their diabetes medication as recommended supported the decisions to be medication adherent. The discussion chapter will place the findings of the present study in the context of the existing literature reviewed and summarized in the first two chapters. The implications section will discuss how to utilize this valuable information to improve the lives of others who struggle with diabetes medication adherence.

Discussion of Findings

Resiliency theory provided the lens through which the data was interpreted and eco-systems theory provided the framework for viewing resiliency. Thus, resiliency was observed at the individual, family and friends, community (e.g. healthcare providers, co-workers, church relationships), and society levels (e.g. historical context, policies, health insurance). Moreover, resiliency theory allowed for a focus on strategies and mechanisms

that promote diabetes medication adherence. This perspective is innovative in that prior studies have taken a problem-oriented focus concerning medication adherence, focusing on barriers rather than overcoming those barriers. When identifying patterns associated with resilience, there is a need to understand the related concepts of competence, adversity, asset, and risk (Yates & Masten, 2004). Participants were faced with adversity and risk (diabetes management) and responded with competence (adherence to medication) by exerting their assets (successful problem-solving strategies). Many participants stated they had no choice but to take their medication, but certainly there are people with diabetes making the choice not to manage diabetes every day. The lens of resiliency allows the researcher to explore the participants' responses to adversity, with the intention of disseminating those resilient strategies to the larger community.

Key findings related to resiliency and individual mechanisms consistent with diabetes medication adherence include (1) participants' negotiation of diabetes stigmatization; (2) acceptance of the diabetes diagnosis; (3) high level of self-efficacy as evidenced by their expressed confidence in their ability to engage in self-care behaviors (including medication adherence) necessary to control blood glucose; (4) understanding of the ramifications of diabetes self-management; and (5) garnering support from both formal and informal resources.

Participants were motivated to avoid poor outcomes and debilitating consequences associated with failure to adequately control blood glucose (e.g. progression of disease, amputations, blindness); however, they were equally likely to cite their desire to increase well-being and improve their health as motivation to engage in medication adherence. Furthermore, participants had a deep understanding of the value of

all aspects of diabetes self-management (e.g. medication adherence, healthy diet, adequate activity, glucose monitoring, regular doctor visits) today leading to an improved quality of life in the future. The strategies used to improve their diabetes self-management varied, suggesting there is more than one pathway to managing diabetes and approaches to diabetes self-management need to be developed by the patient in conjunction with HCPs.

Stigmatization of Diabetes

Many participants were unaware that there was a familial history of diabetes until they were diagnosed and chose to talk with a family member, usually their mother. Julia and Vanessa were excellent examples of how learning about genetic factors and the extent of diabetes in their families led to medication adherence. Kirkman et al. (2015) suggest patients who were newly diagnosed with diabetes were significantly less likely to be adherent to diabetes medication. This may be, in part, because they are in denial and have not accepted the diagnosis of diabetes; therefore, acceptance of the diagnosis is of primary importance for diabetes self-management.

Once the family history of diabetes was disclosed, this set in motion a cavalcade of potential support from other family members. Moreover, many participants were committed to breaking the silence and openly discussed diabetes prevalence and prevention with their own children. Link and Phelan (2001) suggest an examination of stigma should extend to incorporating how "people artfully dodge or constructively challenge stigmatizing processes" (p. 387). The resilient people in this study were, in essence, choosing not to participate in the acknowledged diabetes-related stigma present

in the African American community and breaking the silence by challenging stigmatizing processes (Link & Phelan, 2001).

The stigmatization of diabetes may have its roots in slavery and the treatment of sick slaves. Plantation owners viewed African Americans as property and, therefore, were compelled to care for the sick (Andreae, 2009; Collins, 1853). However, resources allocated to care for sick slaves were dependent upon the perceived worth of the worker in terms of productivity (Haller, 1972; Sellers, 1994). Sick slaves faced a conundrum; they were forced to reveal their weakness (being sick) at the risk of being negatively labeled as malingering or deceptive (Andreae, 2009). Furthermore, if slaves were chronically ill, the owner may devalue their worth and sell or trade them for a healthier worker (Andreae, 2009). This historical view of sickness may persist to modern times without conscious assent by African Americans. Thus, the perception of diabetes as a weakness or burden that must not be revealed continues. Moreover, in every sense of the word, stigmatization is seen as an "attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted discounted one" (Goffman, 1963, p. 3) in the narratives of many participants, particularly Alpha women. Many participants chose to eschew stigmatization either by keeping their diagnosis private or telling others to increase support. Furthermore, participants empowered themselves through knowledge to engage in diabetes self-management.

Knowledge Empowerment and Diabetes Medication Adherence

The second aim of this study was to identify internal and external factors that enable African Americans with diabetes to go beyond adherence and to develop a broader understanding of the disease and how to manage it. The development of this broader

understanding of diabetes was interwoven in the interviews and focus groups. Many participants comprehensively discussed diabetes self-management, which suggested they possessed a deep understanding of their condition and the various means necessary to fully engage in self-management (e.g. diet, activity, glucose monitoring, regular HCP visits).

Psychosocial barriers consistently related to diabetes self-management and resiliency were self-efficacy, locus of control, and social support (King et al., 2010; Sarkar, Fisher, & Schillinger, 2006). Ajzen (2002) asserts that self-efficacy focuses primarily with the person's assessment of the relative ease or difficulty of performing a given behavior, whereas locus of control measures the extent to which a behavior is under the control of the individual versus an external agency. Furthermore, Bandura (1977) proposed that the confidence patients have in their ability to competently perform a given health behavior will determine which behaviors they will adopt. Thus, high self-efficacy is consistently associated with improved health outcomes (Krichbaum, Aarestad, & Buethe, 2003; Sarkar et al., 2006).

The assets of self-efficacy and internal locus of control are consistent with a resiliency perspective and were invaluable for participants in this study. While the questions targeted medication adherence, many participants discussed related issues that suggested they possessed a deep understanding of their condition and the various means necessary to competently engage in self-management (e.g. diet, activity, glucose monitoring, regular HCP visits). For these participants, knowledge was foundational to knowing what activities were most important to adequately manage blood sugar; therefore, the vast majority of participants attended DSME classes at least once (83%).

“Diabetes self-management education (DSME) is the ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care” (Funnell et al., 2011, p. 1). Participation in DSME classes is known to significantly improve adherence to medical treatment and is associated with lower A1C (Brunisholz et al., 2014). Furthermore, for every dollar spent on DSME, a savings of up to \$8.76 can be realized (Klonoff & Schwartz, 2000). Li et al. (2014) found extremely low participation in DSME, defined as attendance in one class, during the first year after a diabetes diagnoses (6.8%). The findings from Li et al. (2014) are not consistent with standards of care (ADA, 2014), which suggest DSME should be received by patients upon initial diagnosis of diabetes and whenever needed to increase self-efficacy. For example, when patients are initiated onto insulin therapy, DSME can assist in this transition by providing a specific understanding of the side effects of insulin and guidelines for safe utilization.

Furthermore, ADA (2014) suggests DSME must provide care for psychosocial issues to optimize positive outcomes. Participants in this study were very likely to utilize DSME as a cost effective intervention and many informants attributed their success with diabetes self-management to participation in DSME. Best practices would suggest patients with diabetes need to be provided with a prescription for DSME and prompted to take advantage of this important resource that stresses developing individual strategies to adequately address psychosocial concerns and personal action-centered strategies to engage in lifestyle and behavior changes to effectively manage diabetes (Funnell et al., 2011; Haas et al., 2013).

Many participants cited foundational knowledge was obtained from attending DSME classes; however, these resilient participants often sought information through a

variety of resources including HCPs (e.g. physicians, pharmacists, nutritionists, certified diabetes educators) and through other resources (e.g. Internet, brochures, books). In addition, some had strong connections with friends and family with diabetes.

Support

While type and degree of social support varied for participants, all participants saw the need for support in learning about diabetes and adequately managing it. On one end of the continuum, the Alpha women and Trustee men were content to have a limited support system with the primary support of HCPs and maybe the inclusion of spirituality; Networking women and Warrior men were intentionally widening their support system to include an array of friends, family, and other resources, albeit for different reasons.

Family and friends. Alpha women self-identified as strong, self-sufficient, independent African American women. This disposition of being the one who cares for others may create a barrier to identifying and accepting support, even the same type of support they would give to those they love. For example, Alpha females perceived “nagging” had a negative connotation. Furthermore, these women perceived attempts at supportive behaviors by others (e.g. attending diabetes education classes, reminding them to take medication, invitations to exercise) as judgmental and not supportive for them.

Conversely, “nagging” did not bother Black men; in fact, they perceived it as evidence that someone loved and cared for them. However, Trustee men were less likely to see a need to increase support from others and were more likely to manage diabetes with only assistance from HCPs. Warrior men perceived social support, even nagging, in many forms as another tool in their kit to fight diabetes. Similarly, Networking women welcomed support from others.

Thus, for African Americans, supportive behavior may be conceptualized very differently according to gender. This difference in perception may be related to traditional roles; African American women have often functioned in the caregiver role in addition to financially supporting the family (Tang et al., 2008; White, 1983).

Tang et al. (2008) utilized the symbolic interaction theory (Blumer, 1969) as the framework for understanding individual behavior in the context of subjective experience in the social exchange. For example, an individual's perception and thus, the interpretation of social support have an effect on how a given interaction is received. This framework is useful in understanding gender differences in social support in the African American participants. Consistent with these findings, Tang et al. (2008) found African American men in their study reported more social support and diabetes-care related social support than their female counterparts. Moreover, the men were more satisfied with the quality of the support and perceived support as more positive compared to the women.

The second Diabetes Attitudes, Wishes, and Needs (DAWN2) was a global survey that sought to better understand the experiences of people with diabetes and their families with the aim of improving diabetes self-management through psychosocial mechanisms (Kovacs Burns et al., 2013; Nicolucci et al., 2013). Furthermore, Peyrot et al. (2014) specifically examined U.S. data to understand ethnic differences in psychosocial attitudes among non-Hispanic whites, African Americans, Hispanic Americans, and Chinese Americans. Overall, a higher perception of social support, a larger diabetes-related support network, and a sense of availability of support were associated with improved psychological outcomes for all people with diabetes. However, Peyrot et al. (2014) found salient differences in social support; African Americans and

Hispanic Americans reported having larger support networks. But, minority groups reported more diabetes-related family arguments than non-Hispanic whites. Peyrot et al. (2014) hypothesized more frequent family arguments may be related to increased interaction with family members in minority groups.

Thus, the social worker, as part of the healthcare team, can be a catalyst for reshaping the patient's view of social support, helping the person with diabetes to appraise various types of behaviors perceived as constructive and caring versus those that feel negative or critical. It may be beneficial for African American people with diabetes to understand the potential benefits of increased social support and learn how to clearly communicate their needs and wants when it comes to diabetes-related support. Moreover, the social worker is uniquely trained to integrate caregivers (spouses, other family and friends) into the support network and teach them to effectively communicate support, which may assist the person with diabetes to better engage in diabetes self-care, including medication adherence. Furthermore, social workers can assess and integrate additional salient support as identified by the person with diabetes, which may include spirituality.

Spiritual support. Many participants expressed the value of spirituality and support received from their personal relationship with God. Some participants, like Vanessa, articulated a long history of spiritual support when facing other challenges throughout her life course. Others simply acknowledged a general sense that God was watching out for them. The range of personal spiritual connection was observed and the absence of acknowledging institutional support from the Church was salient. Therefore, while the Church, as an institution, may contribute to a personal spirituality, participants did not specifically attribute diabetes-related support to their church. A few participants

discussed the presence of health programming (health fairs, educational events), but did not perceive a personal need for those types of events.

This does not mean the Church is irrelevant in assisting people with diabetes in medication adherence and broader aspects of diabetes self-management. To the contrary, the Black Church has a vital role in encouraging congregants and the larger community to care for their bodies as the “temple of the Holy Spirit” (I Corinthians 6:19 New King James Version) and to highlight the benefits of “bear one another’s burdens” (Galatians 6:2) to increase social support. Historically, the Black church is the center of African American life (Billingsley & Morrison-Rodriguez, 2007; Hill, 2007) and has been concerned with holistic health (Warren & Charles, 2011); many Black churches prioritize health as an integral part of their ministry and outreach to the larger community. The Church can be a catalyst for change by openly discussing diabetes management, reducing stigma, highlighting individuals who are managing diabetes well, and fostering support for all people with diabetes.

Faith-based health interventions, which target prevention and treatment of Type 2 diabetes in African Americans, have been shown to improve health outcomes (Collins-McNeil et al., 2012; Johnson et al., 2014). Moreover, there are culturally compatible resources available for African American churches to initiate DSME classes. For example, Project POWER is a faith-based program designed to provide Black churches with activities throughout the year to increase awareness and improve the health of those living with diabetes and their families (ADA, 2014). There are six modules facilitated by Project POWER ambassadors, lay members of the church, designed to empower African Americans to learn more about diabetes prevention and management.

Consistent implementation of these types of programs can support the mission of the Church and improve health outcomes for the African American community.

Practice Implications

The process of diabetes medication adherence is complex and rife with obstacles that patients must overcome successfully in order to maintain medication adherence. A salient finding from this research is an identification of the multistep process of diabetes medication adherence and the hurdles present for participants. Moreover, the role of healthcare professionals in adherence to diabetes medication is evolving; the role of the patient is increasing and physicians must partner with other HCPs to achieve optimal results. Evidence-based interventions are providing HCPs with a myriad of options to increase diabetes medication adherence in the context of team-based healthcare.

The Process of Medication Adherence

Sustaining medication adherence is not a simple task. Participants described an eight-step process of medication adherence that must be successfully navigated in order to maintain adherence. Participants provided strategies used to solve common barriers in this process. HCPs can widely distribute these strategies to those who find themselves stuck at one or more points in this process. Moreover, the process can provide a road map for patients and HCPs to discuss and identify and resolve the point(s) of challenge for patients.

Several salient strategies can be extended to those who struggle with adherence. For example, one strategy involved scheduling appointments well ahead of time to reduce lost work time and ensure renewing a prescription in a timely manner. This simple idea

can be implemented in conjunction with the HCP staff to assist in making timely appointments and facilitate ongoing care and medication adherence.

Pharmacists were an integral part of the successful medication adherence equation (Brennan, 2012; Grant, Devita, Singer, & Meigs, 2003; Jacobson, 2014; Kalsekar, Sheean, & Peak, 2007; Krass Taylor, Smith & Armor, 2005; Mazroui et al., 2009; Odegard, Goo, Hummel, Williams & Gray, 2005; Phumipamorn, Pongwecharak, Soorapan, & Pattharachayakul, 2008). In addition to refilling prescriptions, study participants utilized this resource for additional information and support. Improving communication among all HCPs will provide a safety net for the patient and timely renewal of prescriptions leading to increased medication adherence. Furthermore, the utilization of pharmacies as a center for education has tremendous potential. It may be an innovative place for social workers to partner to increase adherence. Social workers could communicate with patients to better understand whether non-adherence is intentional or unintentional; thus, tailoring an intervention and offering resources to fit the patients' needs.

Moreover, participants described various ways of setting up the home environment for success including clustering medication and supplies in a central area and attaching taking medication to an already existing behavior (e.g. meals, brushing teeth, time of day). Participants were particularly adept at overcoming their fear of needles and challenges concerning unwanted side effects. The strategies used by these participants are generally accessible for other patients and can be distributed to those who struggle with medication adherence due to apprehension and unwanted side effects.

The Role of Healthcare Professionals in Medication Adherence

The practice of medicine is evolving at a rapid pace and includes an examination of past processes and roles, which may not be serving the patient in modern times.

Andersson, Garfield, Eliasson, Jackson, and Raynor (2014) reviewed 103 publications that included randomized control trial (RCT) interventions to improve medication adherence in diverse populations. Moreover, the RCT interventions had to include a defined role in intervention delivery for pharmacists and/or physicians. Pharmacists typically assumed the role of patient educator and made medication treatment recommendations. Of these interventions, 66% led to improved medication adherence, while 73% led to improved clinical outcomes (e.g. lower A1C). Andersson et al. (2014) recommend HCPs receive specific training in developing a concordant approach with patients where a treatment plan meets identified needs of the patients, thus, increasing adherence. Moreover, Andersson et al. (2014) suggest non-adherence to a medication prescribed by a HCP may be an appropriate informed decision by the patient.

Patient–physician roles in medical decision-making. Participants in this study used a number of different ways of relating to their HCPs. It is important to note that many patients had high expectations for their HCPs and clearly communicated when they had questions or problems concerning their medication. The patients in this study can be located at various points on the shared decision-making continuum in their own decision-making process with their HCPs. Moreover, they provided important insights into the value of patient-centered care and factors related to a trusting relationship with HCPs (e.g. listening, answering questions, spending adequate time). Peyrot et al. (2014) found African Americans were more likely to report experiencing patient-centered care than

their white counterparts. Furthermore, Peyrot et al. (2014) found a strong association between patient-centered care and diabetes empowerment; thus, people with diabetes who were engaging in patient-centered care were significantly more likely to experience diabetes self-care empowerment.

A salient finding in the physician-patient relationship was the lack of guilt participants expressed about transitioning to insulin. Their HCPs were able to help them understand the need for a different treatment (insulin) to supplement or replace their OHAs. This respectful, non-judgmental strategy made the need for insulin a natural part of the progression of diabetes rather than a failure on the part of the patient. While many participants immediately accepted advice from their doctor to begin insulin therapy, several participants stated it took some time for them to be ready to initiate insulin therapy. Regardless of the initial response, patients were included in this decision and their views were respected.

Makoul and Clayman (2006) suggest that decision-making runs along a continuum; at one extreme is the healthcare professional unilaterally making the decision without patient input and at the other extreme is the patient making medical decisions without consulting the HCP (Figure 14). Makoul and Clayman (2006) suggest better outcomes are related to shared decision-making, which lies somewhere in the center of the continuum.

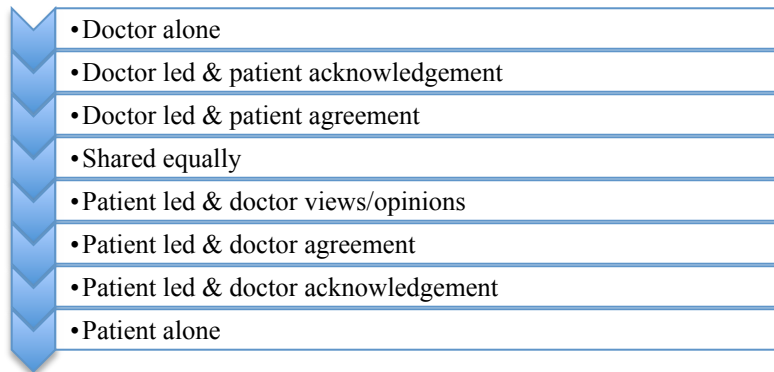


Figure 14. Integrative Model of Shared Decision Making in Medical Encounters
 Source: Makoul & Clayman (2006, p. 307)

While there was variation in the study participants' expectation for participation in the medical decision-making, ideally, the concordance approach to patient care would be implemented to elicit various opinions resulting in a decision agreed upon by both patient and physician (Horne et al., 2005). This approach insists that healthcare team members reach beyond simply asking patients if there are any questions to making certain the patient understands his or her options and can articulate what he or she would like to do. Epstein and Street (2011) suggest "helping patients to be more active in consultations changes centuries of physician-dominated dialogues to those that engage patients as active participants" (p. 101). Furthermore, Epstein and Street (2011) suggest understanding the specific proximal outcomes of patient-centered care that might contribute to improving adherence and self-care is essential. It is imperative that patients take part in the decision-making process and that may take some persistence and coaching on the part of the healthcare team. This may be particularly important for Trustee men who described passivity and compliance in their relationship with their physicians.

Pharmacists' role in adherence. A salient finding was the study participants' value of the pharmacist as an integral part of their healthcare team. Many informants in this study reported feeling comfortable asking questions of their pharmacist and expressed appreciation for information gained through these interactions. Furthermore, informants who went to the pharmacy on a monthly basis were likely to pick up educational materials in the form of brochures and free magazines while obtaining their prescription medication. Increasing the role of the pharmacist in improving medication adherence is consistent with findings from this study.

According to the 2013 Boehringer Ingelheim Pharmacy Satisfaction Pulse Survey, which included 5,455 patients diagnosed Type 2 diabetes, nearly 20% of patients filled prescriptions more than 50 times in the past year (Jacobson, 2014). Moreover, 76% of patients were very comfortable discussing Type 2 diabetes with their pharmacist and 85% considered the role of their pharmacist to be important in their overall health (Jacobson, 2014). Furthermore, 52% of people with diabetes were more interested in receiving written information about their medical condition and general health topics than were other pharmacy patients (42%). This is consistent with participants in this study that often asked questions of their pharmacist about their medication and diabetes management in general. Moreover, many participants looked forward to obtaining free magazines and pamphlets from the pharmacy that provided reliable information about diabetes self-management.

In 2012, 24% of American diabetes patients utilized mail order pharmacies as their primary resource for obtaining prescription medications (Jacobson, 2014). Furthermore, Jacobson (2014) reported that people with diabetes were significantly more

likely (66%) to exercise their option for a 90-day medication refill compared to other patients (48%). People in this study who showed a preference for mail order pharmacies felt obtaining their medication without interruption and with as little effort on their part as possible was integral to their ability to be medication adherent. HCPs may want to explore a mail order pharmacy as an option for those who have difficulty remembering to reorder or experience challenges in obtaining their medication (e.g. transportation barriers, no delivery by pharmacy in town).

Pharmacists have an opportunity to increase their role in the health of their patients and play a pivotal role in promoting medication knowledge and adherence. For example, many pharmacies currently offer helpful services to their patients such as free diabetes screening, medication refill reminders, diabetes education classes, information about insurance coverage, and money saving programs (Jacobson, 2014). Moreover, Brennan (2012) evaluated a pharmacy-based intervention aimed at improving diabetes patients' adherence rates. This large study included an intervention group with 5,123 patients with diabetes and a control group of 24,124 matched patients with diabetes. The intervention involved both mail order and retail pharmacists who were provided with information on patients' adherence to medication (Brennan, 2012). When pharmacists used this adherence information to encourage patients, diabetes patients' medication adherence rates were increased by 2.1%, compared to the control group (Brennan, 2012).

Moreover, patients who received counseling in the retail setting benefitted more than those who received phone calls from pharmacists based in mail-order pharmacies, suggesting face-to-face interaction between the pharmacist and patient contributed to the increase in adherence (Brennan, 2012). Furthermore, the pharmacy-based interventions

were cost-effective; the return on investment was about \$3 for every \$1 spent on the intervention (Brennan, 2012).

Due to the promising findings regarding pharmacist led interventions in conjunction with the positive regard study participants reported for their pharmacists, expanding the role and scope of practice for pharmacists may lead to increased medication adherence. Pharmacists can assist patients with Type 2 diabetes improve adherence to antihyperglycemic medications (Omran, Guirguis, & Simpson, 2012) and increase patient knowledge (Grant et al., 2003; Kalsekar et al., 2007; Krass et al., 2005; Mazroui et al., 2009; Odegard et al., 2005; Phumipamorn et al., 2008). Moreover, pharmacist-led interventions not only improved medication adherence rates, but some also demonstrated lower A1C as compared to the control group (Mazroui et al., 2009; Odegard et al., 2005; Phumipamorn et al., 2008).

Patient education was the most common strategy used in pharmacist-led interventions (Grant et al. 2003; Kalsekar et al., 2007; Krass et al., 2005; Mazroui et al., 2009; Odegard et al., 2005; Phumipamorn et al., 2008). The educational component focused on improving the patient's knowledge and understanding of various diabetes medications through a discussion of the expected benefits and potential side effects. Beyond an increased understanding of diabetes medication, education included increasing knowledge and awareness of other aspects of diabetes including risk for complications and healthy lifestyle changes (Omran et al., 2012). These educational components were delivered through face-to-face meetings between the pharmacist and patient and some involved supplementation with written information (Mazroui et al., 2009; Odegard et al., 2005; Phumipamorn et al., 2008).

Team-based health care. The participants in this study relied upon HCPs to assist in improving their health and described high expectations for these interactions. Alpha women wanted an “investment” in their health; Networking women wanted “caring” physicians; Warrior men needed “direct” communication; and Trustees relied heavily upon HCP expertise. These ideas are not mutually exclusive; in fact, it is possible to train HCPs and other members of the healthcare team to be invested experts with communication styles that are both direct and caring. Participants in the research study benefitted from a team-based approach to their care, which included a variety of HCPs.

Primary care physicians are in short supply (Phillips, Bazemore & Peterson, 2014); therefore, the time is right for the advancement of an integrated team approach to patient care. To best serve patients in the future, it is necessary to innovate the healthcare delivery system to be truly patient-centered.

Healthcare models, such as Iora, are on the cutting edge of innovation in healthcare delivery (Fernandopulle, 2013; Landman, Aannestad, Smoldt, & Cortese, 2014). Iora reinvented the model for healthcare by eliminating the fee for service billing and focusing on a team-based approach utilizing health coaches (Fernandopulle, 2014; Landman et al., 2014). Social workers are perfectly suited for the health coach role, which includes patient advocacy, assisting with behavior change, and support. In fact, the Iora approach requires a social worker as a vital component of the healthcare team. In pilot testing, this model has demonstrated improvement in patient experience, health outcomes, and lower healthcare costs (Fernandopulle, 2013).

Patient needs and challenges are comprehensively assessed using the eco-systems model. The strengths of patients are weighed and interventions to improve health are

discussed as a team, which includes the patient; the health coach supports the patient in carrying out the agreed upon plan (Fernandopulle, 2013). Increasing patient support can include more frequent visits with a health coach or social worker, activities with other Iora community members, and individualized solutions to medication adherence struggles.

The findings from this study have potential to impact the training of the next generation of HCPs. In our current culture of healthcare reform we need innovative notions concerning how to define and achieve patient-centered care, which improves outcomes and reduces costs is invaluable.

Interventions to Improve Medication Adherence

The patients in this study believed medication adherence was crucial in preventing or eliminating diabetes-related complications. Some participants reported times in the past when they intentionally decided not to take their medication due to denial or fear of needles; others were in circumstances in which affording the medication was the issue and they were unintentionally non-adherent.

The findings from this study stress the importance of interventions tailored to individual needs. Moreover, practitioners must distinguish between intentional non-adherence and unintentional non-adherence; there is a difference in intervention when a patient lacks motivation to take medication as opposed to one who is experiencing barriers to taking medication. Furthermore, it is crucial to address an individual's specific situation in order to improve adherence (Clifford, Garfield, Eliasson, & Barber, 2010).

Modifying patient beliefs about diabetes medication is a promising avenue for improving diabetes medication adherence. Broadbent, Donkin, and Stroh (2011) found

patients hold specific beliefs about diabetes management and the relative importance of diet, exercise, and medication adherence concerning outcomes and perception of risk for diabetes-related complications. Patients ranked medication as the most important aspect of diabetes management; moreover, they rated medication adherence as more important than either diet or exercise (Broadbent et al., 2011).

Segal, Leach, May, and Turnbull (2013) suggested that in addition to medical management, access to psychosocial care is required if clinical targets for diabetes management are to be met; this is especially true for underserved populations. Wailoo (2006) suggests the experiences of disease by African Americans are "designating hidden invisible taints. . . and thereby reinforcing broader prejudices and policies" contributing to health disparities in America (p. 533). Thus, policies that may contribute to disparities in prevention and outcomes of diabetes need to be honestly assessed for discrimination.

Social workers can be a valuable part of healthcare teams, as they possess distinctive training in culturally appropriate psychosocial care: relationship skills useful in improving communication with other healthcare professionals and significant others; effective behavioral change and coping skills; and expertise in understanding how ecological systems influence people with diabetes (DeCoster, 2001; Karls & O'Keefe, 2008; Segal et al., 2013; Snoek et al., 2011). Social workers can make substantial contributions to the creation and teaching of DSME classes; furthermore, they can communicate the need for culturally appropriate psychosocial components of care in addition to foundational knowledge (DeCoster, 2001). In fact, social workers' behavioral science training that includes instruction in behavior modification, coping skills, and both

stress and time management is a perfect companion to the traditional biological and self-management skills training in many DSME programs (DeCoster, 2001).

Furthermore, assisting patients with chronic conditions requires a more complex approach beyond basic information. Haynes, Ackloo, Sahota, McDonald, and Yao (2008) suggest interventions delivered by HCPs such as nurses and pharmacists were worthy of future research. Patients need to understand potential side effects and implications of long-term treatment. In addition to information, reminders via texting, telephone follow up, and additional supervision may help patients to develop habits that lead to long-term adherence (Haynes et al., 2008). Furthermore, Haynes et al. (2008) suggest some patients may benefit from individual counseling, family therapy, or crisis counseling, which could be expertly provided by social workers.

Overcoming barriers to adherence. An enhanced understanding of barriers to adherence has led to the development of the AIDES method (Table 11). This approach incorporates information gathered from 153 studies of medication adherence interventions (Horne et al., 2005). In particular, social workers and diabetes educators can be trained to assess patient needs concerning medication adherence using the AIDES method. This method provides a unified forum for identifying challenges for patients and working with them to create a plan that leads to improved medication adherence. The data from the informants in this research study can be used to create a menu of options to assist with problem solving at each juncture.

Table 11. The AIDES Method for Improving Adherence to Medications

A	Assessment: Assess all medications
I	Individualization: Individualize the regimen
D	Documentation: Provide written communication
E	Education: Provide accurate and continuing education tailored to the needs of the individual
S	Supervision: Provide continuing supervision of the regimen

Source: Horne et al. (2005), p. 384

The social worker can target individual, familial, or broader aspects of the environment by utilizing the AIDES method. Social workers trained in health education and behavioral changes have the opportunity to address diabetes self-management from a fresh perspective. Social workers can assist patients in creating a self-management plan that leads to acceptance of their condition and increases self-efficacy, key elements related to adherence.

Motivational interviewing. Participants described the process of diabetes medication adherence, which included self-awareness resulting in lasting behavioral change. Resnicow and Page (2008) suggest “mini-epiphanies” may be a catalyst for behavior change (pp. 1382-1383). One tool that shows promise in promoting these epiphanies and engagement in patient-centered care is motivational interviewing (MI). MI began as an evidence-based approach in addiction and recovery models in the 1980s (DiClemente & Prochaska, 1998). The stages of change characteristics are in Figure 15. This approach acknowledges gaps between knowledge and behavior choices (Christie & Channon, 2014; DiClemente & Prochaska, 1998). In fact, this approach extends permission to make no change at all if that is the choice a person wishes to make at a given time.

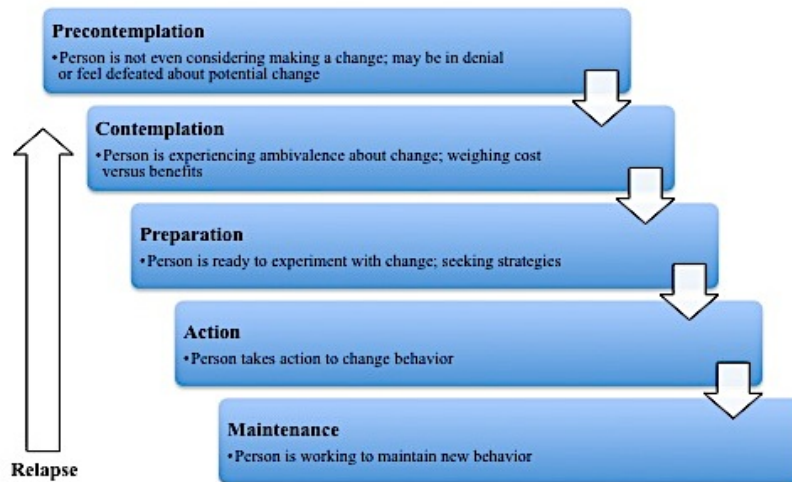


Figure 15. Stages of Change Characteristics

In addition to other HCPs, social workers are poised to utilize MI to engage patients in healthy lifestyle adaptations and empowerment. The MI trained practitioner guides the conversation, providing a listening ear that intentionally explores dissonance and stresses exploring the benefits of making changes to improve outcomes (Christie & Channon, 2014). Techniques used by MI trained specialists include “reflective listening, shared decision making, and eliciting change talk” (Resnicow & McMaster, 2012, p. 1). In diabetes self-management, the client would identify an aspect of self-care that he or she would like to improve; this may not be the behavior that the HCP would choose. Hood, Rohan, Peterson, and Drotar (2010) suggest a comprehensive approach, which includes social, emotional, and behavioral change, yields the best outcomes.

As behavioral health specialists, social workers can become a regular part of integrated healthcare teams (Colvin, Nelson, & Cronin, 2012). Diabetes-related distress, which can be defined as the patient’s concerns about self-management of diabetes, perception of support, emotional burden, and access to quality health care

(Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008) has been associated with higher A1C and decreased engagement in diabetes self-management. Wardian and Sun (2014) found factors related to higher diabetes-related distress include lower self-efficacy and less HCP support. These findings are consistent with study participant reports of the value of HCP support and self-efficacy in diabetes medication adherence. On a more comprehensive level, patients must have confidence in their ability to manage diabetes to fully engage in diabetes self-management including medication adherence (Cherrington, Wallston, & Rothman, 2010). Social workers are uniquely trained to assist patients in overcoming distress, which could enable people with diabetes to overcome barriers to adherence and engage in other aspects of diabetes self-management.

There is no one-size-fits-all formulaic approach to medication adherence for people with diabetes. Findings from this study suggest that there are many pathways to adherence and knowing what the individual needs is imperative. The typologies reiterate this notion and provide a way of assessing the personal needs of the patient. Clinicians may be able to identify which typology is more closely associated with the patient and target intervention and support accordingly. The resiliency and eco-systems theories provide guidance in identifying patient strengths and targeting the particular level within the eco system that needs to be changed.

The emerging typologies allow clinicians to see the person in environment and assess what type of intervention or support may increase self-efficacy in medication adherence. Table 12 provides a snapshot of informant attributes at all levels of the eco-system and corresponding typologies. For example, Trustee men and Alpha women would potentially benefit from comprehensive HCP support (e.g. diabetes educators,

nutritionists, exercise physiologists), as they are not interested in increasing informal support through family and friends. Moreover, HCPs have tremendous influence with these two typologies; therefore, being directive and making specific suggestions for improving health are likely to be followed. There are salient differences between these two typologies in their interaction with HCPs. Taking time to answer Alpha women’s questions is imperative in this process. Whereas Trustee men may not ask questions, HCPs should not assume they understand and may be well advised to confirm understanding by engaging in a dialogue and providing written information.

Table 12. Qualitative Clustering of Emerging Typologies by Attributes and Eco-system Level

Eco-system level	Attributes	Emerging Typologies			
		Alpha	Networking	Warrior	Trustee
Individual	Gender	Female	Female	Male	Male
	Diabetes Characterization	Weakness or vulnerability	Small part of life	Enemy	Respect it
	Acceptance of diagnosis	Yes	Yes	Yes	Yes
	Understand seriousness of diabetes	Yes	Yes	Yes	Yes
Family and friends Support	Informal	Low	High	High	Low
Community	HCP support	High	Moderate	Moderate	High
Societal	Diabetes-related stigma	Keep quiet	Openly discuss	Openly discuss	Keep quiet
Summary		“Strengthen me”	“Join me”	“Equip me”	“Tell me”

Policy Implications

Participants in this study shared narratives about times when the cost of medication affected their ability to be adherent to diabetes medication. Moreover, the period of non-adherence was often associated with poorer health outcomes. Furthermore, participants expressed that low co-pays assisted in medication adherence by not forcing

them to make difficult financial choices. These findings support the notion that policymakers, healthcare personnel, insurers, and patients should consider actively supporting low cost programs designed to improve diabetes medication adherence (Roebuck et al., 2011). Moreover, medication adherence programs need to be culturally appropriate; the message must resonate with communities adversely affected by the outcomes of medication non-adherence.

Structural level devaluation of individuals with diabetes can restrict access to healthcare resources (e.g. DSME, medication, quality healthcare) (Link & Phelan 2001; Wailoo 2006). Moreover, at the individual level structural barriers can prevent seeking necessary healthcare (Link & Phelan 2001; Wailoo 2006). Policy and programming must be based on sustaining health and improving quality of life.

The Patient Protection and Affordable Care Act

On October 1, 2013, open enrollment in the Patient Protection and Affordable Care Act (ACA) marked the most ambitious expansion of access to healthcare for adults age 18-64 in the United States. An analysis of the Gallup Healthways Well-Being Index 2012-2014 data demonstrated a decrease in the percentage of Americans who are uninsured following implementation of the ACA with 20% in 2012 compared to slightly more than 16% in April 2014 (Sommers et al., 2014). Arizona participated in the Medicaid expansion through the ACA Federally-facilitated Marketplace (FFM), which provided Medicaid coverage to low-income adults beginning January 1, 2014 (Long et al., 2014; Sommers et al., 2014). While the effect of this momentous healthcare provision is in its infancy, it has the potential to provide access to affordable healthcare for millions of Americans.

Hill, Abdus, Hudson and Selden (2014) found that adults included in the recent expansion of Medicaid had similar or better health than those enrolled prior to ACA. Healthier adults in the program have the ability to balance expenses for Medicaid; therefore, affording states the capacity to provide adequate healthcare to both healthier adults and those who have diagnosed chronic conditions such as diabetes (Hill et al., 2014).

Long et al. (2014) used data from the Health Reform Monitoring Survey (HRMS) to determine changes in health insurance coverage over the previous year. Between September 2013 and March 2014, there was a decrease of 2.7% in the number of uninsured adults, which translates to approximately 5.4 million people. In states that expanded Medicaid, insurance coverage increased 4.7 percent for adults with a family income of $\leq 138\%$ of the federal poverty line (FPL), which were targeted by ACA Medicaid expansion (Long et al., 2014). Moreover, middle-income adults (139 to 399 percent of FPL) in these states were able to take advantage of the subsidies offered through the Marketplace and health insurance coverage increased by 3.6 percent for this population (Long et al., 2014).

In spite of these gains, a disparity in health insurance coverage persists in states like Arizona with expanded Medicaid, as 12.4% of all American adults remain uninsured (Long et al., 2014). The burden is borne disproportionately with nearly one-third (27.8%) of low-income adults uninsured and 11.4% of middle-income adults sans health insurance coverage (Long et al., 2014). Moreover, people with diabetes who are poor and low income disproportionately bear the burden of high out of pocket costs for medication and other health services (Li et al., 2014). In addition, non-white, non-Hispanic (13.8%) and

Hispanic (27.1%) adults are less likely to have health insurance than their white non-Hispanic (7.1%) counterparts (Long et al., 2014).

Reducing or Eliminating Copays for Medication

Some participants discussed the inability to afford their diabetes medication as the primary cause of periods of medication non-adherence. Furthermore, a few discussed complications experienced during this time were critical to their current and future health outcomes. For some people with diabetes, the cost of their life-saving medications puts an undue burden on their ability to be adherent. Those who are publicly insured (Medicare and Medicaid) include patient populations such as the elderly and low-income groups, who may be especially vulnerable to medication non-adherence when required to contribute copays on a fixed income (Li et al., 2014). Moreover, not taking prescription medication has potential to increase morbidity and healthcare costs elsewhere in the system according to a meta-analysis by Sinnott, Buckley, David, Bradley, and Whelton (2013), which demonstrated an 11% increased odds of medication non-adherence for publicly insured populations who had to supply a copayment. Policy-makers need to understand that medication non-adherence has the potential of adverse clinical outcomes and enormous negative economic repercussions.

Brennan and Studdert (2010) suggest that policy makers were prudent in designing the ACA, which addressed the issue of medication non-adherence in elderly populations. While the full impact of the ACA may not be realized for many years, Kaplan (2011) suggests Medicare recipients will experience a shrinking of the “donut hole”, which currently goes into effect once the total cost of prescription drugs reaches \$2,830. Patients who are in the “donut hole” are responsible for the full cost of their

prescription drugs until the cap of \$6,440 is reached and then enrollees pay no more than 5%. While the “donut hole” does not completely close under the current ACA phase, an enrollee’s out of pocket responsibility is scheduled to decrease from 100% of the cost of prescription medication to 25% by 2020 (Kaplan, 2011).

Furthermore, the ACA provides for programs that specifically address medication adherence (Kaplan, 2011). It will be increasingly imperative that consumers understand provisions in the ACA that relate to their own healthcare; therefore, pharmacists, physicians, case managers, and other HCPs must be able to accurately communicate information related to medication adherence, which includes copayments, diabetes medication adherence classes, interventions, and other programs and technology that can assist in ordering prescription refills and remembering to take prescription medication.

Even though many participants currently had some form of insurance coverage, they discussed times when the cost of medication copays prevented them from obtaining their diabetes medication. Chernew et al. (2008) examined the effect of lowering medication copays on adherence in an environment where private insurance is provided to all employees. This promising avenue for reducing the cost of prescription medications is Value-based Insurance Design (VBID), which proposes improving health outcomes by using financial incentives to promote more cost effective options and increased consumer choice. In the intervention group, copayment rates were eliminated for generic drugs and reduced by half for brand-name preferred drugs (from \$25 to \$12.50) and brand-name non-preferred drugs (from \$45 to \$22.50). There was a substantial increase in diabetes medication adherence (13%) for the intervention group as compared to the control group (Chernew et al., 2008).

Current cost containment approaches tend to shift increased medication costs onto patients; however, increased cost sharing among insurance providers and corporate partners may lead to improved medication adherence and greater access to potentially life-saving medications. Employers may benefit in increased attendance and lower overall costs associated with absenteeism. Furthermore, the cost associated with an increase in the use of prescription medication may be offset by the decrease in other medical services such as emergency room visits and hospitalizations, related to medication non-adherence. Given that African Americans have higher rates of diabetes, poorer glycemic control than whites, and more diabetes-related comorbidities (Heisler, et al., 2007), measures to reduce cost-related barriers to diabetes medication have the potential to lower overall costs and improve diabetes-related health outcomes for African Americans.

Limitations

This study was conducted with a small group (23 participants) in an urban area in Arizona where about 5.7% of the population is African American (U.S. Census Bureau, 2014). This represents a particularly small population, especially in terms of the United States as a whole. Therefore, transferring findings from this study to other African Americans must be done with caution. While many findings are not culturally bound (e.g. setting up the environment for success, attaching medication taking to already established routines, the process of medication adherence) and some are consistent with other literature about promotion of medication adherence, the stigmatization of diabetes and reticence of family to discuss the diagnosis may be more prevalent in this cultural

context. However, these findings may illuminate characteristics found in other cultural groups that may be useful in understanding adherence to medication.

Furthermore, the researcher does not suggest that the emerging typologies are exhaustive; in fact, it is entirely possible there are additional typologies that are adherent to diabetes medication. In addition, this study only included African Americans, there is no way of knowing whether these typologies are culturally bound or may apply to other cultural groups. Moreover, even though the typologies clustered according to gender, it is possible that they are not gender specific. For example, there could be Alpha men, Networking men, Warrior women, and Trustee women. In addition, identification of an emerging typology required at least two people; there were four women that did not cluster into a particular typology, which leaves room for additional typologies that could be identified in future research. Thus, caution should be exercised in generalizing the emerging typologies to other cultural groups outside of African Americans in the Southwest.

Furthermore, the researcher acknowledges the insider/outsider concept. As a person with diabetes, she occupies an insider perspective; however, she is not African American or Black and has made a valiant effort to engage in understanding the cultural perspective through a review of the literature, asking for clarification from informants, and engaging in discussions of findings with a community cultural partners. Moreover, being female may have been a barrier in interviewing male participants in ways that are difficult to assess.

Moreover, the researcher does not assume that mechanisms and strategies can be extended to adherence to other medications. The researcher has provided rich description

and context for readers to make their own decisions regarding the utility of this study for their own work with other populations and with medication adherence for those with other illnesses.

Research Implications

Future research may want to conduct a similar study with other cultural groups or African Americans in another region of America (e.g. South or Northeast) to determine if there are other factors contributing to medication adherence in different cultures. The methodology of this study and theoretical lens of resiliency can be used to uncover other culturally grounded strategies that can be incorporated into DSME targeting disparate populations. In fact, in addition to race, the differences in rural versus urban resiliency and strategies may yield interesting findings.

Moreover, the inclusion of a focus group(s) of healthcare providers may yield innovative strategies and support already successfully utilized to improve medication adherence that could be extended to patients who struggle with medication adherence. Use of strategies uncovered in this study may be able to increase medication adherence and thereby, decrease complications from inadequate glucose control, and reduce healthcare costs.

Moreover, the mechanisms leading to diabetes medication adherence need to be tested to determine the utility of extending these strategies to those who struggle with diabetes medication adherence. Hill-Briggs et al. (2006) suggest problem-solving skills and engagement in self-management are significantly associated with increased medication adherence. Thus, creating a menu of options for each phase of the process of

medication adherence may be useful in assisting HCPs to suggest potential solutions for patients.

Furthermore, an examination of the emerging typologies and their potential usefulness in assisting African American patients with medication adherence may be interesting. For example, Black patients could be presented with the four typologies as narratives to choose which one might be most relatable for them in managing their diabetes. Their choice of typology could provide insight into how to best work with these patients. Moreover, people with diabetes (or other chronic illnesses) who are not Black may be represented in these typologies to some degree. Future studies may want to ascertain how culturally bound these emerging typologies are.

Potentially modifiable risks such as self-efficacy, beliefs about necessity for medication, patient-physician relationship, social support, and conceptualization of diabetes all factor into adherence (Zeber, 2011). Therefore, these findings may be able to inform the creation of a scale for diabetes medication adherence. For example, the degree to which a person with diabetes accepts the diagnosis may be associated with medication adherence. Furthermore, social support has been associated with increased adherence and improved outcomes; our study suggests a difference in perception of social support among typologies that may be salient in increasing support for those who feel more isolated; thus, perception of supportive behaviors may be useful in creating a support system for a person with diabetes.

Furthermore, an investigation of other areas of diabetes self-management may yield interesting findings. For example, interviewing people with diabetes who have been able to effectively lose weight and maintain weight loss for a long period of time may

lead to knowledge, attitudes, and beliefs that are necessary to achieve such a remarkable result. Those with diabetes have additional barriers to weight loss such as medication side effects and insulin resistance, which may necessitate unique strategies. An in-depth look at the exercise and dietary approaches along with support may be enlightening. Moreover, the long-term strategies used by these people may be extended to others who struggle.

Conclusions

In conclusion, the use of resiliency theory to better understand diabetes medication adherence extends this theoretical perspective into a new paradigm. While medication adherence has been primarily viewed through a deficit perspective, the resilience of those who are adherent to diabetes medication allows for the illumination of mechanisms related to adherence, which can be extended to others who are struggling. Strategies utilized by these remarkable people are culturally appropriate and may have utility in other cultural groups.

Individual and broader environmental mechanisms associated with adherence to diabetes medication must include integrated care for African Americans with diabetes to improve medication adherence and other aspects of diabetes self-management. At the minimum, the healthcare team may need to include the patient, physician, social worker, pharmacist, diabetes educator, family and friends. While an individualized plan for diabetes treatment may include broader support (e.g. spirituality, fitness experts, nutritionists), there are basic elements associated with diabetes medication adherence. At an individual level, these elements include acceptance

of the diagnosis, DSME to increase self-efficacy and knowledge of diabetes self-management, and formal and informal support systems tailored to the individual.

The emerging typologies suggest that there are multiple paths to diabetes medication adherence. It is not a matter of forcing a person into a particular mold; rather the HCP must respect the natural bent of the patient and tailor the intervention to the individual. For example, if a HCP is working with an Alpha female, it might be best to suggest private diabetes education, trusted web-based resources or print materials and not push her to reveal her diabetes diagnosis to others until she is comfortable doing so. Additionally, not everyone desires social support from family and friends to the degree that Networking women and Warrior men would want; therefore, allow Trustee men and Alpha women to share their health status and needs at their own pace without judgment.

Moreover, several broader influences were identified. One influence included diabetes-related stigmatization in the African American community. Recruitment for this study suggested many African American people with diabetes continue to experience obesity and diabetes-related stigmatization and, therefore, may not be open to discussion of their condition. This may pose safety risks and reduced avenues for support and assistance. The participants in this study were primarily open to talking with others about diabetes and largely agreed that family members need to know about the family medical history in order to protect themselves. The reduction or elimination of stigmatization may allow for increased support for African Americans with diabetes, thus, improved diabetes self-management.

The Black church may be able to play an important role in reducing stigma and disseminating accurate knowledge about diabetes. A number of faith-based, cultural-

grounded interventions are available to increase awareness, provide reliable diabetes information, and promote support for people with diabetes. These programs are consistent with African American church missions for holistic care over the life course.

Engaging in shared decision-making and problem solving has the potential to put the patient at the center of the treatment plan and provide exemplary patient care. The role of the healthcare team cannot be overstated. Participants in this study wanted HCPs that were strong communicators; this included physicians, pharmacists and diabetes educators. Communication skills were often assessed by the HCPs' ability to attentively listen to the patient. HCPs have an obligation to provide treatment and medication options to the patient and prescribe DSME for all people with diabetes (ADA, 2014). Furthermore, improving communication among all HCPs might provide a safety net for the patient and timely renewal of prescriptions leading to increased medication adherence. Social workers can partner with other HCPs to promote a more patient-centered approach to increasing medication adherence and other diabetes self-management behaviors.

An eight-step process of diabetes medication adherence derived from participants' narratives must be successfully navigated in order to sustain adherence to medication. Furthermore, it is important to assess whether non-adherence is intentional or unintentional (Clifford et al., 2010). Social workers are uniquely trained to assist patients and other HCPs to discuss and identify the point(s) of challenge for the patient. Furthermore, social workers and diabetes educators can be trained to assess patient medication adherence needs using the AIDES method (Horne et al., 2005). MI shows promise for assisting patients in identifying their goals and moving toward successfully

achieving stated goals (Christie & Channon, 2014). Both of these methods provide a forum for identifying challenges for patients and working with them to create a plan that leads to improved medication adherence. For patients who desire to improve medication adherence, salient strategies can be suggested from a menu created to assist in brainstorming strategies that may be adopted by the patient.

Furthermore, healthcare programming and policy is changing at an unprecedented pace in America. The ACA introduced the potential for more Americans to have health insurance coverage and assistance with prevention and treatment programs than in previous times and provides programming designed to improve medication adherence. Moreover, increased coverage for medication is an integral part of the ACA, which includes provisions to eliminate the “donut hole” by 2020 (Kaplan, 2011). Most participants in this study were receiving assistance with medication costs through health insurance (e.g. Medicaid, commercial insurance, Medicare, Tricare). Even with this coverage, several spoke of past and present burdens of out of pocket costs associated with medication.

Although challenges to improving medication adherence in the African American community exist, there are people who have already overcome these challenges. The resilient people in this study achieved diabetes medication adherence in spite of considerable challenges (e.g. low income, no insurance, lack of transportation, low social support). They may have a stronger voice with those who are struggling than they believe. Furthermore, they may be able to assist in decreasing stigmatization and promoting diabetes medication adherence in their own community and broader society, thereby reducing the consequences of poorly controlled blood glucose.

As the resilient strategies and mechanisms for diabetes medication adherence are distributed throughout the local community, the empowerment of the community to tackle the issue of diabetes medication non-adherence remains to be seen. The preliminary findings from this study have been shared with HCPs, non-profit health organizations, government health agencies, and Black church leaders. Consistent with the CBPR approach, the researcher will continue to work with African American community partners and participants to disseminate findings to those who can use the information.

In this era of patient-centered care, there must be an effort to expand the roles of disciplines providing diabetes care. The role of the community in determining novel approaches to complex problems needs to be integrated into these healthcare models as well. Moreover, it is imperative that new models of healthcare delivery be explored to determine how to best serve patients with diabetes and improve outcomes for disparate populations.

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APPENDIX A

ARIZONA STATE UNIVERSITY IRB APPROVAL

To: Flavio Marsiglia
UCENT

From: Mark Roosa, Chair *MR*
Soc Beh IRB

Date: 04/26/2013

Committee Action: Exemption Granted

IRB Action Date: 04/26/2013

IRB Protocol #: 1304009075

Study Title: Doctoral Dissertation Research: Diabetes Medication Adherence in African Americans

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2) .

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.

APPENDIX B
SCREENING QUESTIONS

1. Do you ever forget to take your diabetes medicine?
 yes no
2. Are you careless at times about taking your diabetes medicine?
 yes no
3. Sometimes, if you feel better, do you stop taking your diabetes medicine?
 yes no
4. Thinking about the past week, how often have you **not** taken your diabetes medicine? _____

Scoring: Adherence is defined as a negative response to 1-3, no more than 2 doses missed over the past week.

Ethnicity

- | | |
|---|---|
| <input type="checkbox"/> African American/Black | <input type="checkbox"/> Asian |
| <input type="checkbox"/> Non-Hispanic white | <input type="checkbox"/> American Indian/Alaskan Native |
| <input type="checkbox"/> Hispanic/Latino | |

Gender

- Male Female

Age _____

Do you have Type 2 diabetes?

- yes How long? _____
- no

What medication(s) do you take for your diabetes?

- Only pills Only insulin Both pills and insulin

Insurance

- | | |
|---------------------------------------|---|
| <input type="checkbox"/> No insurance | <input type="checkbox"/> AHCCCS |
| <input type="checkbox"/> Medicare | <input type="checkbox"/> Commercial insurance |

What is the highest level of education you have completed?

- < High school High school College

What category of yearly income best describes your household?

- less than 25,000 25,000-50,000
 50,000-75,000 more than 75,000

I would be willing to talk about my experience with diabetes in a (check all that apply)

- Focus group
 Individual interview

If so, please provide the **best** way to contact you.

Phone number: (_____) _____

Email: _____

APPENDIX C
QUESTIONS FOR FOCUS GROUPS AND INTERVIEWS

Individual

1. How did you find out for sure you had diabetes? (Adversity & Risk)
2. How did you feel about it when you were told you have diabetes? What did you say? What did you do? (Asset & Risk)
3. How do you take care for yourself now that you have diabetes? (Competence & Asset)
4. When you did have to take medication, what did you do? (Adversity)
5. When your doctor told you needed to take insulin. How did you feel about taking insulin? (Adversity & Risk) What did you do? (Competence & Asset)
6. What helps you take your medication(s) as prescribed? (Competence & Asset)
Everyone forgets things sometimes. What do you do if you forget? (Risk & Adversity)
7. What things make it difficult for you to take your medication(s)? (Adversity & Risk) How do you handle those difficulties? (Competence & Asset)
8. How do you get your medication(s) and supplies to care for your diabetes? (Risk & Asset)
9. What makes it easier for you to take your medication(s)? (Competence & Asset)

Family & Friends

1. What did your family and friends feel when they heard you have diabetes? What did they say? What did they do? (Risk & Adversity)
2. How have your family helped you to manage your diabetes? (Asset & Competence)
3. How have your friends helped you to manage your diabetes? (Asset & Competence)
4. How have your neighbors helped you to manage your diabetes? (Asset & Competence)

Community and Society

1. What did you know about diabetes before your diagnosis? (Assets & Competence)
2. What is your relationship with your doctor and any others who treat you for

- diabetes like? (Asset, Competence & Adversity)
3. Who else helps you with your diabetes? (Asset)
 4. How does your insurance help in caring for your diabetes? How does your insurance make it more difficult to care for your diabetes? (Asset & Adversity)
 5. Where have you gotten information about diabetes and your medication(s)? (Asset & Competence)
 6. Is there anything else you would like to say about caring for your diabetes that I have not asked about? (Asset)

*Ideas shared will be written on an easel pad for all focus group participants to see. Prompts will include a restatement of concepts already discussed and then asking, “Anything else?”

APPENDIX D
RECRUITMENT FLYER

Would you help us understand
Living with Diabetes
from **your** point of view ?



We are looking for
African Americans who
have Type 2 diabetes

If you qualify and participate in the discussion, you will receive \$50



We are inviting people like you to participate in a **focus group** of 4-6 people to talk about diabetes from your point of view. The discussion will take about 2 1/2 hours so that you and others will have plenty of time to talk about and share your experiences. Everybody will be invited to add thoughts, ideas, and suggestions about things that have worked for them (or that haven't) so we can have a really good discussion about how you feel about diabetes and how you manage it.

To see if you are eligible to participate, please contact Jana Wardian at jwardian@asu.edu or call 602-478-9325.



ASU Southwest Interdisciplinary
Research Center
ARIZONA STATE UNIVERSITY

APPENDIX E

ASU INFORMED CONSENT: FOCUS GROUP

Dear Community Member:

I am Jana Wardian from Southwest Interdisciplinary Research Center (SIRC) at Arizona State University. I am working with Dr. Flavio Marsiglia to conduct small study, or exploration, to better understand how people with diabetes in the African American community think about managing diabetes and medication(s). We are asking you to help us understand living with diabetes from **your** point of view.

We are inviting you to participate in a focus group of 4-6 people to talk about diabetes. The focus group will take about 2 1/2 hours so you and others will have plenty of time to talk about and share your experiences. Everybody will be invited to add thoughts, ideas, and suggestions about things that have worked for them (or that haven't) so we can have a really good discussion about how you feel about diabetes and how you manage it.

Because it is an exploration, the research team doesn't have any opinions or ideas about any of this, so we are hoping to learn what is most important from your point of view. During the focus groups, you will help us deepen our understanding about the general knowledge about diabetes in African Americans, talk about how you manage diabetes, and who or what helps you to take your medication(s).

You have the right not to answer any question,
and to stop participating at any time.

Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. To participate in the study, you **must** be 18 or older and identify as an African American with diagnosed Type 2 diabetes. In addition, you must be taking insulin to manage diabetes.

Although there are no direct benefits to you, possible benefits of your participation are the opportunity to share in an interesting conversation with people in your community about diabetes and increase your personal knowledge of diabetes management. Your responses in this exploration will be documented to allow researchers to review the discussion in greater detail. Feedback from sessions will be used to inform culturally competent strategies to increase diabetes medication adherence in the African American community. It is not likely that there will be risks or discomfort to you during your participation.

The discussion won't be confidential, but we will **never** use your name
in any of our reports or in any of our presentations.

Since focus groups will consist of approximately 4-6 participants complete confidentiality cannot be maintained. Although no personal information will be asked during the focus group, all members will be asked to observe confidentially during and after the session to promote honesty and build trust within the group and community.

Interview sessions will be recorded to make sure that your words stay as you used them so that others do not misinterpret your comments. Your responses will be anonymous. All notes from audio tapes of sessions and field notes will remove names and substitute made-up names to safeguard data and remove all possible information to identify participants.

The research team will make sure that others know what we find out, but what you tell us will be combined with other interviews. The results of this study may be used in reports, presentations, or publications but your name will not be used.

All hard copies of data, including written notes and audiotapes, will be stored in SIRC secured data storage, Suite 700, University Center, Downtown Phoenix campus. Data will be kept for 10 years, and then all hard copies will be shredded. After transcription of the audio recordings, they will be erased using appropriate technology at the time.

If you have any questions concerning the research study, please contact the research team at: Jana Wardian at JWardian@asu.edu or (602) 496-0700 or Dr. Marsiglia @ marsiglia@asu.edu. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

By signing below you are agreeing to participate in the study.

Signature

Date

By signing below, you are agreeing to be audio recorded.

Signature

Date

APPENDIX F

ASU INFORMATION LETTER: INDIVIDUAL INTERVIEW

Dear Community Member:

I am Jana Wardian from Southwest Interdisciplinary Research Center (SIRC) at Arizona State University. I am working with Dr. Flavio Marsiglia to conduct small study, or exploration, to better understand how people with diabetes in the African American community think about managing diabetes and medication(s). We are asking you to help us understand living with diabetes from **your** point of view.

We are inviting you to participate in personal interviews to talk about diabetes. The interview will take about 1 1/2 hours so you will have plenty of time to talk about and share your experiences. You will be invited to share thoughts, ideas, and suggestions about things that have worked for you (or that haven't) so we can learn more about how you feel about diabetes and how you manage it.

Because it is an exploration, the research team doesn't have any opinions or ideas about any of this, so we are hoping to learn what is most important from your point of view. During the focus groups, you will help us deepen our understanding about the general knowledge about diabetes in African Americans, talk about how you manage diabetes, and who or what helps you to take your medication(s).

You have the right not to answer any question,
and to stop participating at any time.

Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. To participate in the study, you **must** be 18 or older and identify as an African American with diagnosed Type 2 diabetes. In addition, you must be taking insulin to manage diabetes.

Although there are no direct benefits to you, possible benefits of your participation are the opportunity to help people in your community. Your responses in this exploration will be documented to allow researchers to review the discussion in greater detail. Feedback from interviews will be used to inform culturally competent strategies to increase diabetes medication adherence in the African American community. It is not likely that there will be risks or discomfort to you during your participation.

The interview will be confidential and we will **never** use your name
in any of our reports or in any of our presentations.

Interview sessions will be recorded to make sure that your words stay as you used them so that others do not misinterpret your comments. Your responses will be anonymous. All notes from audio tapes of sessions and field notes will remove names and substitute made-up names to safeguard data and remove all possible information to identify participants.

The research team will make sure that others know what we find out, but what you tell us will be combined with other interviews. The results of this study may be used in reports, presentations, or publications but your name will not be used.

All hard copies of data, including written notes and audiotapes, will be stored in SIRC secured data storage, Suite 700, University Center, Downtown Phoenix campus. Data will be kept for 10 years, and then all hard copies will be shredded. After transcription of

the audio recordings, they will be erased using appropriate technology at the time.

If you have any questions concerning the research study, please contact the research team at: Jana Wardian at JWardian@asu.edu or (602) 496-0700 or Dr. Marsiglia @ marsiglia@asu.edu. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

APPENDIX G

MARICOPA INTEGRATED HEALTH SYSTEM (MIHS) IRB APPROVAL



MARICOPA
INTEGRATED
HEALTH SYSTEM

Count on us to care.

Institutional Review Board

William S. James, M.D.
Chair, Institutional Review Board
Director, MIHS Psychiatry Residency
Training Program
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April 30, 2014

To: Ann Bonpensiero, RD
Jana Wardian, MSW
Department of Diabetes Education

From: Janeth G. Mattox 
Administrator, Institutional Review Board (IRB)

RE: 2014-060: **Doctoral Dissertation Research: Diabetes Medication Adherence in African Americans**

On April 30, 2014 the above project was approved by the MIHS Institutional Review Board (IRB) by expedited review, Category 7.

This approval includes:

- Research Transmittal and IRB Application
- Data Collection Summary
- Focus Groups Informed Consent Form
- Individual Interviews Informed Consent Form
- Living with Diabetes flyer
- Screening Questions
- Prompts for Focus Groups
- Questions for Individual Interviews
- MIHS and federal regulatory items completed by all study staff

Approval Period
April 30, 2014 – April 29, 2015

As Principal Investigator you are responsible for assuring that:

- The approved protocol is followed exactly and prior IRB approval is obtained for any changes (including changes in recruitment procedures, subject, population, location, protocol).
- Any problems are reported promptly to the IRB.

JGM/ana

You may not continue the study beyond the expiration date above. You must apply for reapproval 45 days in advance of the expiration to allow adequate time for IRB review.* After your study has been conducted you must submit a final closure report.*

* Instructions and forms for reapproval and closures are available on the CopaNet.

APPENDIX H

MIHS INFORMED CONSENT: INDIVIDUAL INTERVIEW

AMA

INFORMED CONSENT
Individual Interviews
Diabetes Medication Adherence in African Americans Study

I am Jana Wardian from Arizona State University. I am working with Dr. Flavio Marsiglia on a study to better understand diabetes. We would like to know how African American people think about diabetes and medication(s). We are asking you to help us understand living with diabetes from **your** point of view.

We are inviting you to talk with us about what has worked for you (or what hasn't). We want to have a really good talk about how you feel about diabetes and how you take care of it.

You don't have to answer a question if you don't want to,
and you can stop talking at any time.

You don't have to be in this study. It is your choice. If you choose not to, that is okay. To be in the study, you **must** be 18 or older and be an African American with Type 2 diabetes. You must be taking insulin for your diabetes.

Although there are no benefits to you, it might help others if you share about diabetes. The talk will be recorded to allow us to review the discussion later. Information will be used to help improve diabetes medication adherence for African Americans. It is not likely that there will be a discomfort to you.

We will **never** use your name
in any of our reports or in any of our presentations.

The talks will be recorded to make sure that your words stay as you used them so that others understand what you said. All notes from audio recordings will use made-up names to protect your identity.

The research team will make sure that others know what we find out, but what you tell us will be put together with what other people say. The results of this study may be used in reports, presentations, or writings but your name will not be used.

All hard copies of notes and audio tapes will be stored at ASU in secured storage, Suite 700, University Center, Downtown Phoenix campus. It will be kept for 10 years, and then all copies will be destroyed. The audio recordings will be erased once they have been transcribed.

If you have any questions about the research study, please contact the research team at: Jana Wardian at JWardian@asu.edu or (602) 496-0700 or Dr. Marsiglia @ marsiglia@asu.edu. If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

Participant signature _____ Date _____

Researcher signature _____ Date _____

APPENDIX I

MIHS INFORMED CONSENT: FOCUS GROUPS

AMA

INFORMED CONSENT
Focus Groups
Diabetes Medication Adherence in African Americans Study

I am Jana Wardian from Arizona State University. I am working with Dr. Flavio Marsiglia on a study to better understand diabetes. We would like to know how African American people think about diabetes and medication(s). We are asking you to help us understand living with diabetes from your point of view.

We are inviting you to talk with us in a focus group of 4-6 people. The focus group will take no more than 2 1/2 hours. We want to hear about what has worked for each person (or what hasn't). We want to have a really good talk about how you feel about diabetes and how you take care of it.

You don't have to answer a question if you don't want to,
and you can stop talking at any time.

You don't have to be in this study. It is your choice. If you choose not to, that is okay. To be in the study, you **must** be 18 or older and be an African American with Type 2 diabetes. You must be taking insulin for your diabetes.

Although there are no benefits to you, it might help you to share with other people about diabetes and learn about diabetes management. The talk will be recorded to allow us to review the discussion later. Information will be used to help improve diabetes medication adherence for African Americans. It is not likely that there will discomfort to you.

The talk won't be confidential, but we will **never** use your name
in any of our reports or in any of our presentations.

Since focus groups will have 4-6 participants, we can't be sure others won't say something. Nothing personal will be asked during the focus group. Everyone will be asked to not share with others outside of the group.

Discussions will be recorded to make sure that your words stay as you used them so that others understand what you said. All notes from audio recordings will use made-up names to protect your identity.

The research team will make sure that others know what we find out, but what you tell us will be put together with what other people say. The results of this study may be used in reports, presentations, or writings but your name will not be used.

All hard copies of notes and audio tapes will be stored at ASU in secured storage, Suite 700, University Center, Downtown Phoenix campus. It will be kept for 10 years, and then all copies will be shredded. After transcription of the audio recordings, they will be erased.

If you have any questions about the research study, please contact the research team at: Jana Wardian at JWardian@asu.edu or (602) 496-0700 or Dr. Marsiglia @ marsiglia@asu.edu. If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

Participant signature _____ Date _____

Researcher signature _____ Date _____