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## Walden University

College of Social and Behavioral Sciences

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Florence Okombo

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> > Walden University 2017

Racial Ethnic Health Disparities: A Phenomenological Exploration of African American Adults with Diabetes Complications.

Abstract

by

Florence A Okombo

MS, University of Phoenix, 2009

BS, Fordham University, 2003

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services

Walden University

April 2017

#### Abstract

Racial/ethnic minority groups experience a higher mortality rate, a lower life expectancy, and worse mental health outcomes than non-Hispanic in the United States. There is a scarcity of qualitative studies on racial/ethnic health disparities. The purpose of this hermeneutic phenomenological study was to explore the personal experiences, attitudes, and perspectives of 6 African American adults with chronic health issues related to diabetes through a face-to-face interview. Social cognitive theory and health belief model guided the study. The participants were recruited through purposeful sampling. The data were coded using axial and thematic coding and subsequently analyzed through phenomenological interpretive inquiry. The participants' perceived experiences were summarized in 7 themes (Beliefs and perceptions, denial, attitudes, treatment cost, neighborhood effect, juggling work and family related stress, and need for positive motivation and support). The participants' experiences with their health outcomes were influenced by internal and some external factors that were beyond their control. Social change implications include public policy makers integrating health policies that are designed for socioeconomic inequality in the neighborhood and improving health insurance company policies on treatment copays. Public health and other human services professionals can develop health intervention to assist minorities with chronic health issues to manage their disease and overcome barriers related to the disease.

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#### Dedication

I dedicate this to my Lord and Savior, Jesus Christ for allowing this girl born and raised in a small village in Kenya get to this point. Completing this project would not be possible without His amazing grace and favor. I also dedicate this work to my parents, who have always believed in me and made sacrifices to ensure they educated a girl in a society that did not believe in girl education.

## Acknowledgments

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#### Chapter 1: Introduction to the Study

#### **Background of the Study**

Racial ethnic health disparities is the difference in which minority groups systematically experiences poor health outcome and are of a greater health risk than majority. These minorities are at social disadvantage and experiences discrimination in the society, which influence their health outcome. Research shows that racial ethnic health disparity is a growing public health problem in the United States (Kim, Kumanyika, Shive, & Igweatu, 2010). There are many health disparities across racial/ethnic groups in the United States (Liao et al., 2011). The U.S. Congress passed the Minority Health and Health Disparities Research and Education Act (2000) with the aim of identifying and eliminating health disparities (Webb, Simpson, & Hairston, 2011). However, minorities continue to experience poor health outcomes despite the legislative interest in improving minority health (Webb et al., 2011). According to Kim et al. (2010), the overall health status of U.S, citizens has improved over the past decade, but racial and ethnic health disparities persist. In other words, the legislation did not help improve the lives of the minorities, suggesting the need for further studies on factors that contribute to racial ethnic health disparities.

The United States is a diverse country made up of different racial/ethnic groups. The officially recognized racial categories in the United States are White, African American or Black, American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Guamanian or Chamorro, Samoan, Native Hawaiian and other Pacific Islander, and other Asians (The U.S. Census of Bureau, 2010). The Hispanic and Latino Americans is racially diverse, and it is classified as Hispanic or Latino and non-Hispanic or non-Latino (The U.S. Census of Bureau, 2010). According to the U.S. Census of Bureau (2010), Hispanic or Latino refers to an individual of Mexican, Cuban, South or Central American, or other Spanish culture or origin. Health outcomes are unequally distributed among these diverse racial and ethnic groups in the United States (Brondolo, Gallo, & Myers, 2009; D'Anna, Ponce, & Siegel, 2010; Ford & Airhihenbuwa, 2010; Khang, 2010; Krieger, 2008; Lowcock, Rosella, Foisy, Mcgeer, & Crowcroft 2012; Quinn, Kumar, Freimuth, Musa, Casteneda-Angarita, & Kidwell, 2011), making racial/ethnic health disparities a public health issue in the United States (Cohen, Chavez, & Chehimi, 2010). These findings help support the growing health problem of racial ethnic health disparities that require further studies to help mitigate the disparities.

Racial/ethnic minorities experience poor health indicators including higher morbidity and mortality rates than non-Hispanic Whites (Davis, Cook, & Cohen, 2005), which is a problem to the nation. For instance, Native Americans, African Americans, and Hispanic-Latinos have higher rates of Type 2 diabetes (Bock, 2012; Tuchman, 2011). Racial minority groups were at a higher risk of complication and had severe H1N1 complications than non-Hispanic Whites and Asians (Lowcock et al., 2012; Quinn et al., 2011). African Americans have significantly higher rates of blood pressure and related complications than non-Hispanic Whites (American Heart Association, 2010). According to D'Anna et al. (2010), minorities rate their health status lower than non-Hispanic Whites. This finding suggests that the social injustice experiences of minorities with their health and in health care settings is linked to negative effect of self-rated health, which are based on their emotions as noted by D'Anna et al., (2010).

The number of minorities continues to increase in the United States. The U.S. Census Bureau (2010) reported an increase of 27.3 million people residing in the United States between 2000 and 2010. According to U.S. Census Bureau, the majority of the growth in the total U.S. population was noted among individuals who reported their race(s) as something other than White alone and those who reported their ethnicity as Latino or Hispanic. Brondolo et al. (2009) posited that immigrants and their descendants will account for most of the U.S. population growth, which will further increase the diversity of the U.S. population across and within ethnic groups. The anticipated demographic changes over the next decade augment the value of researching and addressing racial/ethnic health disparities through policy intervention. The efforts to eradicate factors that contribute to racial/ethnic health disparities have implications for the economic and financial status of the country. Minorities' continued higher disease incidence, morbidity, and mortality places the United States in a position of spending more funds on health care than education and infrastructure of the nation (Kim et al., 2010). The United States needs to have healthy citizens who can productively contribute to the country's economic prosperity and growth.

Social determinants of health are the root causes of racial/ethnic health disparities (Hargreaves et al., 2011; Kim et al., 2010). Inequalities in social, environmental, economic, and physical conditions influence health and deprive individuals opportunities for healthy behaviors, such as access to healthy food and access to health care (Brondolo

et al., 2009; D'Anna et al., 2010; Ford & Airhihenbua 2010; Hargreaves, Boccia, Evans, Adato, & Petticrew, 2011; Kahng, 2010; Kim et al., 2010; Robert, 1999). For example, Lowcok et al. (2012) documented that H1N1 hospitalization was associated with living in a neighborhood with high material or total deprivation. Negative health consequences that arise from social injustice are contributors to racial/ethnic health disparities (Brondolo et al., 2009; D'Anna et al., 2010; Ford & Airhihenbuwa, 2010; Khang, 2010; Krieger, 2008; Quinn et al., 2011). For example, Brondolo et al. (2009) noted that racism leads to inequitable access to social, education, and material resources that have direct effects on health. The lack of these resources can contribute to a lack of access to healthy diets and appropriate medical care, which can indirectly influence an individual's emotions (Brondolo et al., 2009; D'Anna et al., 2010). According to Hargreaves (2011), unequal distribution of social determinants of health (ie., food, insecurity and malnutrition, poor housing and environmental conditions, and financial geographic barriers to health care) are social injustice that contributes to racial ethnic health disparities. The United States must ensure health equity for all, especially for the most disadvantaged populations based on the notion of social determinants of health (Kim et al., 2010). However, researchers have not determined whether the ethical arguments of health equity for all have been effectively communicated to the public by law makers (Brondolo et al., 2009). These findings suggest that the health of minorities do not necessarily depend on an individual's lifestyle choices and legislation, but more of focusing on the social inequalities and need for further studies.

The inequitable exposure to environmental hazard has a negative influence on minorities' health (Davis et al., 2005; Hargreaves et al., 2011; Lowcock et al., 2012; Yinusa-Nyahkoon, Cohn, Cortes, & Bokhour, 2010). For example, Yinusa-Nyahkoon et al. (2010) reported that hazardous waste sites and air pollution from exhaust emissions of city buses, which are asthma triggers, are neighborhood hazards that affect the air quality where many African families reside. Living in environments with toxic contamination, and greater exposure to viral or microbial agents in the water, air, soil, homes, schools and parks, has a significant negative impact on the health of African Americans (Davis et al., 2005). In other words, the environments in which the minorities resides influence their ill health, which contributes to racial ethnic health disparities.

Racial and ethnic discrimination in everyday life experiences have been examined by other researchers in an effort to explain racial/ethnic health disparities (Brondolo et al., 2009; D'Anna et al., 2010; Ford & Airhihenbuwa, 2010; House, 2001; Lowcock et al., 2012). For example, House (2001) noted that prolonged psychosocial responses to racism-related stress could lead to heart disease, hypertension, ulcer, and arthritis. Effects of physiological stress can affect the immune system and increase susceptibility to infectious diseases and cancer (Ford & Airhihenbuwa, 2010; House, 2001; Krieger, 2008). Systematic inquiry of the link between perceived racial discrimination in medical exam room by health care staff on physical and mental health have been performed (D'Anna et al., 2010; Ford & Airhihenbuwa, 2010). According to D'Anna et al. (2010), individuals who have experienced discrimination while under the care of medical personnel tend not to adhere to the provider recommendations nor seek further medical attention. Not following medical provider recommendation may lead to poor health outcome (Ford & Airhihenbuwa, 2010) such as diabetes complications (Gumba, 2012). The findings in these studies suggest the need for qualitative studies that explore how the experiences of minorities in health care setting and everyday life experiences influence the minorities' self-care and other health behaviors.

Community socioeconomic status impact to residents' health has also been documented (D'Anna et al., 2010; Kahng, 2010; Najman, Toloo, & Siskind, 2006; Robert, 1999). The individuals residing in socioeconomically disadvantaged communities are physically inactive due to a lack of recreational amenities (Hicken, Gee, Morenoff, Connel, & Hu, 2012; Najma et al., 2006). A lack of leisure time physical activities is a risk factor associated with diabetes and heart disease complications (Gumbs, 2012; Marshall, 2005). According to Najman et al. (2006), a range of risk behaviors that affect health are linked to socioeconomic disadvantage. For example, cigarette smoking, physical inactivity, and obesity are risk factors associated with diabetes complications among socioeconomic disadvantaged individuals (Gumbs, 2012; Hicks et al., 2012; Najman et al., 2006). These risk factors can be detrimental to minorities with diabetes.

Research on racial ethnic health disparities has been performed using survey questions as documented in Chapter 2 of this study. However, qualitative research on the experiences of African American adults with chronic health issues are absent from the literature. In this study, I focused on African American adults with diabetes complications who have health insurance. Given factors that are suspected to contribute to racial/ethnic health disparities such as (a) everyday racism and discrimination in health providers offices, (b) individual lifestyle and health behaviors, (c) a lack of health insurance, (d) environment and neighborhood amenities, and (e) noncompliance to medical personnel recommendation, phenomenological research is the most appropriate design to give voice to African Americans with diabetes complications.

#### **Problem Statement**

Racial/ethnic health disparities is a public health problem that will grow in magnitude as the number of minorities in the United States continues to grow (Office of Minority Health and Health Disparities (OMHD), 2007). Racial/ethnic minorities experience disparities in health access and outcome in six major areas: diabetes, cardiovascular disease, HIV infection/AIDS, immunization and infant mortality, and cancer screening and management (OMHD, 2007). The lack of access to timely medical care due to little or no health insurance is linked to increased morbidity and mortality rates among minority groups (Brondolo et al., 2009; Lowcok et al., 2012; Quinn et al., 2011). Quinn et al. (2011) documented that the percentage of minorities without health insurance in the United States is higher than the percentage of Whites. Furthermore, African Americans and Hispanics report problems getting medical care as soon as they need it more often than Whites in all levels of income (Hargreaves et al., 2011; Quinn et al., 2011). Robert (1999) noted that minorities reported forgoing seeing a doctor and following the doctor's recommendations such as seeing specialists, filling prescriptions, or getting the recommended medical test because of the cost. According to Quinn et al. (2011), individuals without health insurance or a regular source of health care tend to delay medical care and often fail to adhere to medical treatment or recommendations

resulting in negative health outcome. These findings support other research findings noting that lack of health insurance contributes to poor health of minorities (Brondolo et al., 2009; Lowcock et al., 2012).

Racial and ethnic minorities have more health issues and premature death rates as compared to non-Hispanic Whites (Brondolo et al., 2009; Hargreaves et al., 2011; Kim et al., 2010). The Office of Mental Health Department (2007) noted that the Healthy People 2010 was designed to eradicate health disparities and increase quality and prolonged life; but, racial/ethnic health disparities still persist. According to Kim et al. (2010), there has been a decline in deaths that result from diseases for many people in the United States. However, racial/ethnic minorities have not profited from this progress as evidenced by their continued higher disease incidences, morbidity, and mortality (Kim et al., 2010). Kim et al., (2010) findings revealed a need to investigate as to why the minorities have not benefited from the legislation.

The understanding of factors that contribute to the poorer health of minorities, especially African Americans, have changed over time. Yinusa-Nyahkoon et al. (2010) noted that in previous years, there was a prevailing belief that African Americans' biological traits and genetic predispositions were contributors to their poor health. However, researchers began to argue that environmental factors such as exposure to lead paint (Yinusa-Nyahkoon et al., 2010) and outdoor pollution (Quinn et al., 2011) contributed to the poor health of African Americans. With the evolvement of public health perspectives, researchers suggested that health disparities is a complex interaction of various factors, such as environmental conditions, social disadvantage, and biological traits (Yinusa-Nyahkoon et al., 2010). Although theoretical models of the ill health of African Americans evolved over time, researchers continued to perpetuate the concept of individuals' poor lifestyle choices (Smith et al., 2011; Yinusa-Nyahkoon et al., 2010). For example, Smith et al. (2011) posited that the poor health of minorities is a result of poor life choices that some individuals make, which includes, but not limited to, living in poor neighborhoods with poor living conditions that are unhealthy to individuals' health; however, Brondolo et al. (2009) and Yinusa-Nyahkoon et al. (2010) argued that minority individuals, such as African Americans, do not intentionally choose to live in an unhealthy neighborhood, but are forced to live in such an area due to minority social position. Yinusa-Nyahkoon et al. argued that social forces, which include class relationships, economic structure, historical perspectives, political organizations, racism, and social inequalities, shape the conditions in which African Americans reside and form the barriers that influence racial/ethnic health disparities. Yinusa-Nyahkoon et al. argument led to the investigation of social determinants of health in the current study.

Contemporary theorists consider family social circumstances as the primary contextual barriers that contribute to poor health outcomes. For example, according to the ecocultural perspective, health behaviors are bound by cultural beliefs, and what is practical is based on resources and constraints that are available within the ecological context or environment in which families reside (Yinusa-Nyahkoon et al., 2010). Researchers have studied ecological barriers that challenge the health status and illness management of African Americans based on ecocultural perspectives (Yinusa-Nyahkoon et al., 2010). For example, Quinn et al. (2011) examined racial disparities in access to health care in the US H1N1 Influenza, Hargreaves et al. (2011) studied the social determinants of tuberculosis, Hicken et al. (2012) examined the interaction between social disadvantage and environmental health, and Yinusa-Nyhkoon et al. (2010) completed a study on ecological barriers and social forces in childhood asthma management. These studies are discussed in Chapter 2. According to Yinusa-Nyhkoon et al., the common ecological barriers that challenge the health of African Americans include inconsistent or delayed medical care, limited access to medical facilities, financial constraints, exposure to environmental hazards and indoor allergens, discrimination in medical provider office, and inadequate social support. These finding support the notion that social determinants of health contributes to the poor health outcome of the minorities despite of the individual's socioeconomic status (D'Anna et al., 2010; Lowcock et al., 2012).

There is a need to understand the emotional, psychological, physical, attitude, environmental, and social experiences of minority adults with diabetes as they battle this chronic health condition. Several studies have been performed on racial/ethnic health disparities through random examination of minorities with and without health insurance coverage, which is further discussed in Chapter 2. However, there is no known published literature in which researchers have explored factors that contribute to racial ethnic health disparities through evaluating African American adults who have diabetes complications and who had health insurance prior to their initial diagnosis to the time of research. The ill health of African Americans is linked to a lack of health insurance (Hargreaves et al., 2011; Quinn et al., 2011). The Department of Health and Human Services (2012) reported that a lack of health insurance has adverse effect on the quality of minority population health more than any other demographic or economic barrier. The purpose of this study was to explore if the participants had well visits to a health care provider, and if not, the reasons as to why the participants did not have well visits or seek immediate medical attention in spite having health insurance. I also explored whether the participants followed physician recommendations on lifestyle changes and adhered to the prescribed treatment regimen. Psychological, physical, environmental, social, and occupational experiences of African Americans adults battling diabetes complications were explored as well. A hermeneutic study was used to address the problem.

#### **Purpose of the Study**

The purpose of this study was to explore the factors that contributed to the poor health outcomes of African American adults with chronic health issues related to diabetes complications and to interpret the meaning the participants assigned to their personal experiences, attitudes, and perspectives in the context of racial/ethnic health disparities. Six African American adults with diabetes complications who had health insurance prior to their diagnosis were interviewed about their personal experiences with ecological barriers that challenged their health prior to and after receiving the diagnosis of diabetes. The strategies the participants used to cope with the diagnoses and to comply with physician recommendations, and the consequences of the participants' coping strategies, were explored.

#### **Research Questions**

I sought to explore how African American adults with diabetes complication defined their personal experiences, attitude, and perspective with the chronic health issues in reference to racial/ethnic health disparities. According to Creswell (2007), phenomenological research questions are designed to uncover the significance and meaning of the participants' personal experiences. Drawing from this construct, the research question that guided this phenomenological study was the following: How do African Americans adults with diabetes make meaning of their health experiences in the context of racial/ethnic health disparities? In addition to the central question, four secondary questions were included:

- 1. What are the factors affecting lives of African American adults with chronic health illness associated with diabetes?
- 2. How does the experiences of African American adults with diabetes complications affect their behaviors?
- 3. How do African American adults with chronic illness cope with diabetes complications in regards to their environment?
- 4. What strategies do African American adults with diabetes use to cope with their diagnosis and adhere to health care providers recommendations?

The following interview protocol was formulated to support the study: (a) Did the participants have well visits prior to diabetes diagnosis? (b) What prevented the participants from seeking early treatment? (c) What ecological barriers did the participants experience after receiving a diagnosis of diabetes? (d) What situations have

typically influenced the participants' experiences of diabetes? (e) What are the participants' lifestyle? (f) What lifestyle changes did the participant make post diabetes diagnosis? (g) What strategies did the participants use to adhere to health care providers recommendations? and (h) What were the consequences of the participants coping strategies?

#### **Theoretical Framework**

This study was grounded in the social cognitive theory (SCT) and health belief model (HBM). The SCT is a psychological model of behavior that emerged primarily from the work of Bandura (1986). Bandura added to the SCT by advancing cognitive characteristics to behaviorism and environment (Weiten, 1998). Bandura asserted that environment and behavior intertwine. Bandura maintained that the observation of others within social context shapes individuals' characteristic patterns of behaviors. Researchers have applied the SCT to mental and physical health of human functioning (Weiten, 1998). The SCT is used to explain how the individuals' personality, health behaviors related to diabetes, and the environment contributes to racial/ethnic health disparities (Gumbs, 2012; Lowcock et al., 2012; Schulz, Zenk, Young, Neely, & Nwankwo, 2005). In other words, this study focused on how external factors with in the environment and internal factors influenced the health outcome on the African American.

The environment in which African Americans reside influences their negative health behaviors, such as an unhealthy diet, sedentary lifestyle, smoking, and drug use (Brondolo et al., 2009; D'Anna et al., 2010; Ford & Airhihenbuwa, 2010; Khang, 2010; Quinn et al., 2011). The physicians' recommendations for healthy living, especially for individuals with diabetes, include participation in physical activities and consumption of healthy foods (Babey, Hastert, Woistein, & Diamant, 2010). African Americans tend to lead a sedentary lifestyle (Bock, 2012; Gumbs, 2012; Schulz et al., 2005). For instance, Schulz et al. (2005) posited that African Americans with diabetes complications experience challenges with physical activities and eating healthy based on observation of other family members' sedentary lifestyles and dietary practices. However, Khang (2010) argued that African Americans reside in environments with inadequate access to healthy food and physical activities due to their socioeconomic status (SES). The theory provided a lens for understanding the external barriers that the participants in this study experienced. Minorities are at low SES due to their education and employment rate, which negatively affects their health and lifestyle (Robert, 1999; Tuchman, 2011). The cornerstone of SES is critical for diabetes control because insufficient income often leads to undesirable behaviors, such as consumption of fast food meals (Marshall, 2004). Consuming excessive fast food meals often leads to obesity, which is related to the risk of developing diabetes (Gumbs, 2012). These findings help support other research findings that indicate that minorities' health and behaviors are influenced by their low SES, which is linked to racial ethnic health disparities.

Social psychologists initially presented HBM in the 1950s to account for individuals behaviors in regards to using or choosing not to use the available preventive health services, such as immunization and chest x-rays for tuberculosis screening (Campbell, 2001). The psychologists based their ideas on the notion that individuals feared diseases and that the health seeking behaviors were based on the degree of perceived threat (Campbell, 2001). The model is based on the explanation and prediction of health behaviors, focusing on the attitudes and belief of individuals (Campbell, 2001). According to the HBM, individuals take health-related actions based on the individuals' perception of the illness (Campbell, 2001. When an individual perceive that diabetes may have negative health outcome, the individual may alter his/her lifestyle. For example, African Americans with high self-efficacy may have a greater success in giving up some foods and following an exercise regimen (Weiten, 1998). The individual will change his or her lifestyle by engaging in physical activities and eating healthy when he or she believes that following physician recommendations will help him or her to avoid diabetes complications. Some racial/minority individuals may have the desire to follow health care providers' physical activities recommendations, but the neighborhood in which they reside may not provide them with adequate resources for physical activities (Khang, 2010; Marshall, 2005; Schulz et al., 2005). This model provided a lens for understanding the health behaviors, attitudes, and perspectives of the participants and the need for research on intervention strategies for diabetes management for minorities.

#### Nature of the Study

The purpose of this qualitative study was to explore the ecological barriers experiences of African American adults with diabetes complications in the context of racial/ethnic health disparities. Qualitative researchers focus on understanding experiences from the point of view of the individuals (Creswell, 2007). The phenomenological tradition was selected as the best qualitative approach for this study because the approach provided the participants with the opportunity to express their personal account of chronic health issues associated with diabetes. Rudestam and Newton (2007) noted that a phenomenological inquiry is used to delineate and elucidate the meaning of human experiences. Hermeneutical phenomenology was used to explore the ways in which the participants make sense of their personal experiences and the meaning the participants attach to their experiences (Rudestam & Newton, 2007). To gain an understanding of the phenomenon, face-to-face interviews were conducted, analyzed, and interpreted in order to give voice to a sample of African American adults with diabetes complication. I remained watchful of themes that were presented and reflexively interpreted the meaning of the health experiences of the participants.

#### **Definitions of Terms**

*African American*: A person born in the United States having an origin of Black racial groups in Africa (U.S Census of Bureau, 2010).

*Eczema*: A medical condition in which patches of the skin become rough and inflamed with blisters that cause itching and sometimes bleeding (Dictionary.com, 2016).

*Glycated*: A process in which protein within the red blood cells that carries oxygen throughout the body joins with glucose in the blood (Kirkman et al., 2012).

*Hb A1c*: Measuring glycated hemoglobin to get an overall picture of what average blood glucose level has been over weeks or months (Kikman et al., 2012).

*Health literacy*: The degree to which individuals have the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and comply to sometimes complicated disease management protocols (Egerter, Braveman, Sadegh-Nobari, Kahn, & Dekker, 2011). *Hemoglobin*: A red protein responsible for transporting oxygen in the blood (Kirkman et al., 2012).

*Informed consent*: An individual's explicitly expressed willingness to participate in a research project based on a clear understanding of the nature of the research, of the consequences of not participating, and all factors that might be expected to influence that individual's willingness to participate (Creswell, 2009).

*Reciprocal determinism*: The idea that internal mental events, external environments, and overt behaviors all influence each other (Weiten, 1998). According to reciprocal determinism, the environment does determine behavior; however, behavior also determines the environment (Bandura, 1986).

*Racism*: Refers to institutional and individual practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict the lives of those against whom they discriminate by judgment and action (Ford & Airhihenbuwa, 2010; Krieger, 2008).

*Self-efficacy*: An individual's belief or confidence about his or her ability to perform behaviors that should lead to expected outcomes (Weiten, 1998).

*Socioeconomic status (SES)*: The measurement of an individual's social and economic position in relation to other individuals. SES is a multifaced social construct resulting from a combination of indicators including education level, household income, and employment status (D'Anna et al., 2010). *Social determinants of health*: Social and economic conditions, such as income, education, employment, and social support that influence the health of individuals and communities (Lowcok et al., 2012).

*Social stratification*: A concept that ranks people into categories in a hierarchy based on shared socioeconomic conditions (Lowcock et al., 2012). Social stratification results in the unequal distribution of resources in a society based on individual power, privilege, or prestige (Hargreaves et al., 2011).

*Ulcers*: An open sore on an external surface of the body caused by a break in the skin (Dictionary.com, 2016).

#### Assumptions

The participants were recruited from the Hudson Valley region in New York State. I assumed that the Hudson valley region suburban is a vial area for recruiting African American adults with health insurance who have also experienced diabetes complications. I assumed that the participants would be truthful and straightforward in giving an account of their personal life experiences of diabetes-related, chronic health problems in reference to ecological barriers that are linked to racial/ethnic health disparities. I assumed that I would secure African American adults participants who met the criteria and who would be willing to participate in the study.

#### **Scope and Delimitation**

The scope of this study included the phenomenon of factors that contributed to the racial ethnic health disparities experienced by African American adults with diabetes complications. Therefore, the participants' shared personal experiences were analyzed as

they related to factors that contribute to racial ethnic health disparities. Only six African American adults were recruited to participate in this study. More specifically, African American adults who experienced diabetes complications and had health insurance at the time of the diagnosis to present were recruited for this research. African Americans with other chronic health issues and other minorities with chronic illnesses were excluded. The findings in this study are not meant to be generalized due to the limited number of participants.

#### Limitation

This research was limited to acquiring data from African American adults with diabetes complications who had health insurance by the time of they received diabetes diagnosis. The study was limited to use of a small purposive sampling, which is a nonprobability sampling that does not involve the random selection of participants (Creswell, 2007). Qualitative researchers use purpose sampling rather than random sampling in order to obtain information-rich cases (Miles & Huberman, 2005). The limitation of a purposive sample is that the personal/health experiences of the participants may not be representative of all African Americans. However, the goal of this qualitative study was not for statistical analysis or to generalize the findings. Studying information-rich cases, which is referred to as purpose sampling, yield insights and in-depth understanding of the issue under study rather than using empirical generalization (Patton, 2002). The premise of this study was to capture in-depth understanding of racial/ethnic health disparities from the perspectives of African Americans adults with diabetes complications who had personally experienced the phenomenon. Another limitation was

the exclusion of other officially recognized races and ethnic groups other than African Americans. Other minority racial/ethnic groups were excluded because I sought to explore the experiences of African Americans. More specifically, African Americans with diabetes complications who had health insurance at the time of the diagnosis were recruited for the study.

#### Significance of the study

This research is significant because the health of minorities influence the health of the nation, which in turn affects the nation's economy. The U.S Census Bureau (2010) projected that minorities will make up approximately 50% of the U.S population in 2050. The anticipated demographic changes over the next decade augment the importance of researching and addressing racial ethnic health disparities. The efforts to identify contributors of racial ethnic health disparities have lifelong implications for the minorities and for the nation's health. The findings from this phenomenological study of African Americans adults with diabetes complications can make a significant contribution to the existing literature by increasing empirical knowledge and understanding of racial/ethnic health disparities, as told by the participants who have diabetes complications. The study findings have implications for human services professionals such as public health workers and social workers to advocate for the minorities living in unhealthy environments by working with community leaders, government-elected officials, or legislatures to improve the environment in order to promote population health. Human services could use the findings to help support

statewide and community-based policies and environmental changes within minority communities.

#### **Summary**

Racial ethnic health disparity is a public health problem in the United States, warranting study on how ecological barriers and their underlying social forces affect African Americans with chronic health conditions and diabetes complications and how these individuals manage their medical conditions. The United States is a diverse country consisting of different races and ethnic groups. The minorities residing in the United States experiences more health issues and have worse health outcomes as compared to the majority Whites. The minorities are disproportionately hurt by a lack of access to health care and limited or no health insurance (Krieger, 2008). The minorities report forgoing seeing a doctor and following the doctor's recommendations, such as seeing specialists, filling prescriptions, or getting recommended medical test because of the cost (Robert, 1999). Everyday racism and perceived health care provider discrimination are linked to poor health outcome of African Americans. According to House (2001), racismrelated stress may result in physiological issues that could lead to medical conditions, such as heart disease, hypertension, ulcer, and arthritis. Physiological stress can affect an individual's immune system and increase susceptibility to infectious disease and cancer (Ford & Airhihenbuwa, 2010; House, 2001; Krieger, 2008). Individuals who have experienced perceived provide discrimination in examination rooms tend not to seek further medical attention nor adhere to the medical provider recommendations.

Minorities' health are affected by living in environments with toxic contamination and greater exposure to viral or microbial agents in the water, air, soil, homes, schools, and parks (Davis et al., 2005; Prevention Institute, 2002; Yinusa-Nyahkoon et al., 2010). Low SES individuals' health is affected by poor dietary and health behaviors (Khang, 2010; Tuchman, 2011). The access to health care and limited or no health insurance is linked to racial/ethnic health disparities (Krieger, 2008; Quinn et al., 2011). Individuals may delay treatment due to a lack of health insurance. Treatment delay could result in poor health outcomes. Overabundance of research focusing on racial/ethnic health disparities are quantitative and mixed method studies based on self-reported health status and comparison of all the health outcome of all races within the United States Qualitative research was selected to explore the health experiences of African American adults with diabetes complications and who had health insurance in the context of racial ethnic health disparities. .

In Chapter 2, I will present a literature review on studies relative to racial/ethnic health disparities. Chapter 2 provides detailed information on diabetes and factors that contribute to racial/ethnic health disparities in reference to diabetes. Chapter 3 provides a detailed account of the qualitative method of inquiry, specifically the hermeneutic phenomenological research methodology, and an explanation of why other qualitative designs were not suitable for the study research problem. Data collection, management, and data analysis strategies are also presented in Chapter 3. Chapter 4 contains the participants' stories, themes, and answers to the research questions. Chapter 5 contains an interpretation of the study findings, study limitations, and the implication for social change.

#### Chapter 2: Review of Literature

Racial/ethnic health disparities are a public health problem in the United States (Kim et al., 2010; Webb et al., 2011). In studies of health disparities within the U.S. population, African Americans have higher all-cause mortality rate and lower life expectancy (Bock, 2012; D'Anna et al., 2010; Hicken, Gee, Morenoff, Connell, & Snow, 2012; Zheng & Schimmele, 2005). For instance, the mortality rate due to high blood pressure are approximately 15 deaths per 100,000 people for White, but more than 50 per 100,000 for African Americans (Hicken et al., 2012). According to Bock (2012), African Americans have a higher rate of complications resulting from diabetes. Although previous researchers have studied health disparities, research on African Americans with chronic health issues and diabetes complication is scarce. Explicit health disadvantages among racial/ethnic minorities are as a result of higher rate of chronic illnesses, racial attitude and discrimination, a lack of health insurance, communication barriers between patient and health care providers, historical experiences, and exposure to environmental and occupation hazards (D'Anna et al., 2010; Hicken et al., 2012; Quinn et al., 2011). It is unclear whether racial/ethnic minorities experience similar health barriers. This literature review provides the cornerstone for the continued research of racial/ethnic health disparities.

This chapter provides an overview of research related to racial ethnic health disparities. In each section, I present a detailed examination of the knowledge pertaining to the phenomena: literature search strategy and terms, theoretical foundations (SCT and HMB), factors that contribute to racial ethnic health disparities as experienced by
minorities (racism, health behaviors and lifestyle, SES, and environment), and a justification for the research study.

## **Literature Search Strategies**

The literature search for this study commenced in the spring of 2012. The research topic was broad at that time because the topic was a comprehensive study of racial ethnic health disparities. The focus was subsequently narrowed to include only African American adults. The population of the study became more refined due to progress in the literature review. The literature was accessed through the following databases from the Walden University Library: PsycARTICLES (1909-2013), SocINDEX with Full Text (2003-2012), MEDLINE with Full Text (1986-2013), EBSCOhost Research Database, Academic Search Premier, and Nursing and Allied Health Source (1975-2013). Web sites used for the literature review included web sites from the American Diabetes Association, The American Heart Association, the Department of Health and Human Services, the U.S. Census of Bureau, the World Health Organization, and the Center for Disease Control.

The following key terms were used to gather information about racial ethnic health disparities: *inequalities in health in the USA, health inequities, the health of African Americans, the minority health, qualitative studies, health and behavior, the social determinants of health, environment and health, access to health care, racism and health, community health, health intervention and strategies, socioeconomic status effects on health, effects of neighborhood characteristics on health, racial health disparities, racism effects on health, perceived racial discrimination in health care facilities, effects*  of individual behavior on health, diabetes and African Americans, diabetes intervention and treatment, and diabetes prevalence.

#### Diabetes

Diabetes is a health issue in the United States that is problematic for African Americans, even within African Americans with health insurance coverage (Tuchman, 2011). According to the American Diabetes Association (ADA, 2014), 9.3% of the U.S. population has diabetes, and 27.8% of people with diabetes are undiagnosed. Gumps (2012) documented that 61% of incidences and prevalence of diabetes have been noted in the United States, and the rate is expected to double by the year 2050. The Center for Disease Control (CDC, 2005b) reported that deaths due to diabetes accounts for 16 million of all diabetes cases. The data on CDC indicates that diabetes is growing health problem in the United States of America.

Type 2 diabetes is characterized by insulin resistance, malfunctioning of pancreatic beta cell, and increase glyconeogenesis by liver (Gumbs, 20012; Marshall, 2005). According to Kirkman et al. (2012), Type 2 diabetes epidemic is linked to an increase in the rate of obesity. The prevalence of Type 2 diabetes in African American adults is twice as much as in non-Hispanic White adults (Bertera, 2003; Cheng et al., 2012). For example, ADA (2014) reported that 13.2% of African Americans have a Type 2 diabetes diagnosis as compared to 7.6% of non-Hispanic Whites. Diabetes is not only a burden to African Americans, but also costly to the society in terms of disability, mortality, and health care costs. The American Diabetes Association (2009) reported that diabetes prevalence is expected to double by 2034, and the annual spending related to diabetes would be \$336 billion. The total estimated cost for diabetes care in 2012 was \$245 billion (ADA, 2013). Hospital inpatient costs were 41.3% higher among African Americans as compared to non-Hispanic Whites (ADA, 2013). African Americans visit emergency rooms 75% more compared to the diabetic population as a whole (ADA, 2013). The disabled diabetic patients often rely on Medicare to cover the cost of diabetes supplies, which is costly to the U.S. economy. For instance, The ADA (2013) noted that 62.4% of the cost for diabetes care is provided by Medicare and Medicaid, 34.4% by private insurance, and 3.2% by the uninsured patients. This finding indicates that treatment of diabetes is costly to the U.S given the percentage of African Americans with diabetes visiting the emergency room.

The projected increase of diabetes prevalence primarily affects African Americans. African Americans are disproportionately affected by diabetes compared to the general population (Bock, 2012; Cheng et al., 2012; Gumbs, 2012). For example, Gumps (2012) reported that African Americans account for more than 50% of all new Type 2 diabetes cases, while non-Hispanic Whites account for 10% of the Type 2 diabetes population. The prevalence of obesity, genetic traits, insulin resistance, and physical inactivity contributes to African Americans having a high risk for Type 2 diabetes (Cheng et al., 2012; Gumps, 2012; Marshall, 2005). Marshall (2005) noted that, in studies on nondiabetic African Americans, scholars have revealed increase insulin resistance even after adjusting for body weight and fat distribution. Obesity is more prevalent among African Americans than White Americans (Bock, 2012; Gumps, 2012; Marshall, 2005). According to Marshall (2005), obesity is associated with insulin resistance and Type 2 diabetes. Physical inactivity among African Americans contributes to their risk for diabetes (Bock, 2012; Gumbs, 2012; Marshall, 2005). These findings suggest the need to explore factors that contributes to the physical inactivity among African Americans through studying the link between the environment and individual's lifestyle choices. My study used SCT and HBM to explore the external and internal factors that influence African Americans health outcomes.

## **Diabetes Complications**

Diabetes complications include cardiovascular disease, nerve damage, kidney damage, eye damage, foot damage, skin conditions, hearing impairment, Alzheimer;s disease, and gestational issues (Bock, 2012). African Americans experience higher rates of complications from diabetes, including heart disease, kidney disease, stroke, amputation, and blindness as compared to the general population with diabetes (Gumps, 2012; Kirkman, Briscoe, Clark, Florez, & Swift, 2012). The CDC (2011) noted that diabetes is a cause of heart disease and stroke. The risk of stroke is two to four times higher in adults with diabetes than in adults without diabetes (Bock, 2012; Kirkman et al., 2012). In 2004, stroke was noted in 16% of diabetes-related death certificates among individuals aged 65 years or older, and heart disease was noted in 68% of diabetes-related death certificate among adults aged 65 years and older (CDC, 2011). African Americans with diabetes have nearly a 50% risk of developing stroke and death rate as compared to the general population (American Heart Association [AHA], 2012). Diabetes is the leading cause of kidney failure in the United States (Bock, 2012; CDC, 2011). The CDC (2011) reported that 44% of new cases of kidney failure in 2008 among individuals with

diabetes, of which 46% were African Americans. These findings augment the need to investigate factors that contribute to the higher risks of diabetes complications among African Americans.

The CDC (2011) noted that 70% of individuals with diabetes have hypertension, which is a risk factor for heart disease. According to the CDC, in the years 2005 to 2008, 65% of adults aged 20years or older with self-reported diabetes had high blood pressure and/or used prescribed hypertension medications. African Americans have the highest rates of high blood pressure as compared to other races (AHA, 2012; Bock, 2012; CDC, 2011; Gumbs, 2012). For example, the AHA (2015) reported that 46% of African American women and 45% of African American men have high blood pressure as compared to 33% of White men and 30% of White women and Hispanic men and women. Long-term complications such as hypertension develop gradually and could lead to disability or death (Bock, 2012), which can be detrimental to U.S workforce and economy.

Sensory impairment is one of many diabetes complications. One to five older U.S. adults with diabetes self-report visual impairment (Kirman et al., 2012). According to the ADA (2014), individuals with diabetes are more likely to suffer from glaucoma than individuals without diabetes. The rates for adults with diagnosed diabetes who reported visual impairment was 20.7% for African Americans, 17.1 for Whites, and 15.6% for Hispanics (CDC, 2011). The hearing impairment of low and midfrequency sound was twice prevalent in individuals with diabetes as compared to individuals without diabetes (Gumbs, 2012). Hearing impairment is linked to vascular disease and disease of the

nervous system (Kirkman et al., 2012). According to the CDC (2011), 60% to 70% of individuals with diabetes have nervous system disease that causes pain in the feet or hands, slow digestion of food in the stomach, and carpel tunnel syndrome. The diabetic nerve disease contributes to lower extremity amputation (Bock, 2012; CDC, 2011; Kirkman, 2012). For example, 62% of African Americans, 56.6% of Whites, and 50.9% of Hispanics adults with diabetes reported mobility limitations between 1997 and 2011 (CDC, 2011). A number of adults with diabetes suffer from periodontal disease (Kirkman et al., 2012). For example, according to the CDC (2011), about one third of individuals with diabetes have severe gum disease resulting in loss of attachment of the gums to the teeth. These findings show that diabetes is detrimental to the U.S economy in terms of the individuals becoming disabled and are unable to work. For example, Bock (2012) noted that diabetes can damage an individual's blood vessel of the retina, which may lead to blindness. An individual who goes blind may leave workforce due to the disability.

In addition to physical health complications, individuals with diabetes may experience mental health complications. Diabetes is associated with depressive symptoms, such as sadness, a loss of energy, and feeling hopelessness (CDC, 2011; Kirkman, 2012). Depressed patients may have difficulty making choices related to a healthy lifestyle and taking care of themselves, as well as a high risk of mortality and dementia among older adults (Kirkman, 2012). As previously noted, managing diabetes requires self-care and healthy lifestyle to avoid complications, which suggest the need for exploring behavioral factors that contribute to racial ethnic health disparities.

# **Theoretical Foundation**

# **Social Cognitive Theory**

SCT defines an individual's behaviors as triadic, dynamic, or reciprocal interaction of individual's personal factors, behavior, and environment (Bandura, 1986). Bandura (1986) maintained that individuals actively seek out and process information about their environment to maximize favorable outcome. An individual's behavior is determined by the environment in which the individual lives or works, the individual's personal behaviors, and the individual's cognitions. Bandura referred to reciprocal determinism, which emphasizes that behavior influences environment and environment influence behavior. In other words, the environment in which an individual resides may impact the individual's health, and the individual's behavior has an impact on the environment in which the individual resides.

Weiten (1998) stated that, according to reciprocal determinism, internal mental events, external environments, and overt behaviors all influence each other. Individuals can act to alter their environment. Although individuals can alter their environment, social stratification has negative effects on some racial/ethnic groups. Social stratification results into unequal distribution of social determinants of health, which includes, but is not limited to, access to health care, behavioral and biological risks, material living conditions, and psychosocial circumstances (Hargreaves et al., 2011). Bandura further stressed that cognitive structures such as beliefs and expectancies influence and are determined by both behavior and environment (as cited in Weiten, 1998), which refers to the HBM. The HBM can be used to predict individuals health behaviors that affect an individual's willingness to change health behaviors, primarily due to perceived susceptibility, perceived severity, perceived benefit, and perceived barriers (Smith et al., 2011). The model was originally presented in the 1950s by psychologists to provide explanations as to why individuals would or would not use available preventive services, such as immunization and chest x-rays for tuberculosis screening (Campbell, 2001). The psychologists posited that individuals feared diseases and that the health action was based on the degree of perceived threat (Campbell, 2001).

## **Health Belief Model**

The HBM can be used to predict individuals health behaviors that affect an individual's willingness to change health behaviors, primarily due to perceived susceptibility, perceived severity, perceived benefit, and perceived barriers (Smith et al., 2011). The model was originally presented in the 1950s by psychologists to provide explanations as to why individuals would or would not use available preventive services, such as immunization and chest x-rays for tuberculosis screening (Campbell, 2001). The psychologists posited that individuals feared diseases and that the health action was based on the degree of perceived threat (Campbell, 2001).

In perceived susceptibility, individuals do not change their health behaviors unless the individuals believe that they are at risk of health issue or complications (Smith et al., 2011). Perceived severity is the probability that an individual will change his or her health behaviors in order to avoid a consequence that the individual considers to be a serious consequence (Smith et al., 2011). With perceived benefit, convincing an individual to change a behavior without any benefit can be difficult (Smith et al., 2011). For example, a diabetic individual may not stop having a concentrated sweet diet if the individual does not think that doing so will improve his or her life in some way. Perceived barriers include social difficulties such money, medical insurance, a lack of health promoting resources, and health behaviors of the others in the community or social cycle (Smith et al., 2011). This model also includes the concept of cues to action referring to both internal and external events that can influence an individual's willingness to take action and incite behaviors that are observed (Campbell, 2001). These findings help support the point that African Americans health are influenced by environmental and personal barriers that cannot be avoided (Brondolo et al., 2009).

The SCT includes the interaction between an individual's perception and the individual's behavior through self-efficacy and outcome expectancies processes (Elder et al., 1999). Self-efficacy refers to an individual's belief about his or her ability to perform behaviors that should lead to expected outcomes (Weiten, 1998). Both self-efficacy and reciprocal determinism will help explain the reasons why the participants in the study failed to seek immediate medical attention resulting into advanced staged diabetes; strategies that the participants might use to deal with the diabetes diagnosis and to comply with health care physicians' recommendations; and environmental, social interaction, and lifestyle that might influence the participants' strategies. According to Hargreaves et al. (2011), social stratification negatively affects certain racial ethnic groups although these individuals can alter their environment. Social stratification contributes to unequal distribution of social determinants of health, which includes access

to health care, behavioral risks, material living conditions, and psychosocial circumstances (Hargreaves et al., 2011). An individual's health status is impacted by unequal access to health care and healthy diet (Brondolo et al., 2009). These findings help explains how social determinants of health influence the health of the minorities. However, further research is needed to explore individual's experiences and perspectives through a qualitative study that allows a researcher to get a clear understanding of how the participants navigate these factors as they battle diabetes.

Research has been conducted on the factors that are suspected to influence health disparities, such as perceived discrimination in receiving medical care and racial /ethnic disparities in self-rated health status among national random diverse samples (Brondolo et al., 2009; D'Anna et al., 2010; Ford & Airhihenbuwa, 2010); SES, such as education and employment (Robert, 1999; Tuchman, 2011); dietary and health behaviors, such as exercise and cigarette smoking (Khang, 2010; Tuchman, 2011); access to health care and limited or no health insurance (Krieger, 2008; Quinn et al., 2011); language barriers or misunderstanding between health provider and patient (Brondolo et al., 2009; Cohen et al., 2010); and inequitable exposures to occupational and environmental hazards (Hargreaves et al., 2011); but, Krieger (2008) noted that racism unfavorable affects individuals' health, which is evident in racial/ethnic disparities in health.

Behavioral and dietary factors do influence individuals' health, but minority groups are at a disadvantage in health and disease because of social circumstances and environmental factors (D'Anna, et al., 2010; Ford & Airhihenbuwa, 2010; Kahng, 2010; Quinn et al., 2011). Minorities experience an unhealthy environment through inadequate access to healthy food and physical activities (Khang, 20100), which are usually physicians' recommendations for diabetic patients (Babey et al., 2010). Individuals who reside in certain neighborhoods may not have access to healthy foods despite having interest in following health care providers' recommendations (Khang, 2010). A patient may have no confidence in his or her ability to lose weight based on his or her past experience with diets because the patient may have made an effort on several diets in the past without long-term success (Elder et al., 1999). Some individuals may lack the motivation to engage in preventive measures that can increase their self-efficacy (Elder et al., 1999). For instance, an individual may be anxious to self- inject insulin or engage in prescribed physical activities.

# Factors that Contribute to Racial Ethnic Health Disparities Racism

Racism that African Americans experience in their daily lives influence their mental and physical health (Brondolo et al., 2009; D'Anna et al., 2010; Krieger, 2008; Lee, Ayers & Kronnenfeld, 2009). The continued poor health of African Americans despite the overall progress of their lives compels this study to take a look at the role racism may play. A number of racial/ethnic health disparities researchers have focused on multiple dimension of racial discrimination, such as social injustice, effects of everyday discrimination, health care provider discrimination in an examination room, and poor physical and mental health outcomes (Brondolo et al., 2009; D'Anna et al., 2010; Krieger, 2008; Krieger & Sidney, 1996; Le et al., 2009). The researchers have generally utilized the biopsychosocial model to explain the relationship between racism and health. According to Lee et al., (2009), biopsychosocial model maintain that racism cause stress through experiencing discrimination, which in turn produce physical and psychological health issues. The reactivity between racism and psychophysiological is linked to blood pressure and heart rate responses, which leads to stress related disorders such as hypertension and other cardiovascular diseases (Brondolo et al., 2009; Krieger & Sidney, 1996; Mays, Cochran, & Barnes, 2007). Bertera (2003) documented that high blood pressure is associated with internalized racial discrimination.

Krieger and Sidney (1996) study measured effects of racial discrimination on blood pressure among young Blacks and White adults. The survey study examined the relationship between blood pressure and self-reported experiences of racial discrimination and response to unfair treatment. The Black working adults who reported having experienced racial discrimination and typically accepted unfair treatment had a Systolic blood pressure of 7 mm Hg higher than among those who reported having challenged the unfair treatment and racial discrimination. According to Mays et al., (2007) suppressed anger may be a risk factor for high blood pressure. These findings on Krieger and Sidney (1996) add to empirical evidence to the notion that social construction of race/ethnicity, and resultant social discrimination resulting from these constructs and not that biological differences, that seems to shape patterns of blood pressure observed among African American population when compared to Whites (D'Anna et al., 2010). Everyday stress that African Americans experience through racism has a great impact on their mental health (Krieger, 2008). Bertera (2003) maintained that stress threatens individuals' well-being and taxes individuals' abilities to cope with

diabetes complications. Studies show that diabetes is associated with a high prevalence of depression (Gumbs, 2012; Kirkman et al., 2012). According to Kirkman et al., (2012), depression can lead to difficulty with self-care and implementation of healthy lifestyles. Self-care is critical in managing chronic disease, and research evidence shows that diabetes complications can be mitigated through adequate self-care behaviors (Bock, 2012; Chlebowy, Hood, & Lajolie, 2010; Gumbs, 2012; Robbins, Vaccarino, Zhang, & Kasl, 2000).

The social injustice that are mirrored in discrepancies in access to health care, health care providers variation behaviors, and differences in SES are linked to negative health consequences (Mays et al., et al., 2007). According to the perspective of discrimination model, racial/ethnic minority status and health disadvantage is linked to harmful effects of chronic experiences with actual and perceived racial discriminations (Banks Kohn-Wood, & Spencer, 2006; D'Anna et al., 2010; Mays et al., 2007). For example, Banks et al., (2006) examined the link between discrimination and anxiety and depressive symptoms. The data in the study was obtained from a multistage area probability sample of face to face interview of adults residing in three counties in Michigan. Perceived everyday discrimination was assessed utilizing a scale of global perceptions of every day unfair treatment. The respondents were asked how often they experienced depressive symptoms such as sad, hopelessness, and worthless. For anxiety symptoms, the respondents were asked how often they felt nervous, and restless or fidgety. African Americans men in the study reported experiencing more significant discrimination including people being afraid of them and thinking they are dishonest than other men. Discrimination was significantly associated with depressive symptoms. Anxiety symptoms were significantly related to the increased level of depressive symptoms. Overall finding in the study indicated that increased perceived everyday discrimination was significantly associated with both depressive symptoms and anxiety, which is consistent with other research (Berter, 2003; Brondolo et al., 2009; D'Anna et al., 2010). According to Bertera (2003), Feeling of worthlessness may cause an individual with diabetes to ignore special prescribed diet or medication regimen needed to control diabetes symptoms. Researchers have shown that individuals with depression and diabetes have more severe diabetes symptoms than individuals with diabetes alone (Bertera, 2003; Bock, 2012; Gumbs, 2012; Kirkman et al., 2012).

Perceived medical provider discrimination has negative impact on individuals' utilization of health care and possible health outcomes (Brondolo et al., 2009; D'Anna et al., 2010; Lee et al., 2009). Brondolo et al., 2009) stated that the individuals who have been victimized have more dissatisfaction and less trust with medical providers and with the overall healthcare system. Such healthcare providers behaviors undermines efforts to promote health behaviors especially when they spend less time planning and collaborating with patients from ethnic/racial group (Brondolo et al., 2009; D'Anna et al., 2010; Lee et al., 2009). For instance, Bock (2012) completed a personal narrative study of African American man with diabetes. The participant in the study reported that his physician was of no help to him. According to the participant, his physician did not educate him on how to lower his hemoglobin A 1c. The participant figured out a way to stay healthy and was able to lower his hemoglobin A 1c from 13.0 to 6.0 in six months. According to the participant, his physician was shocked with his progress and asked him how he was able to lower his A 1c. The participant was upset that his physician asked him that question because he would have assumed that the physician was the right individual to educate him on lifestyle changes. According to the participant, he changed this particular doctor to a more understanding physician.

Perceived discrimination in the healthcare setting has been associated with poor health outcomes of African Americans (D'Anna et al., 2010; Ford & Airhihenbuwa, 2010; Lee et al., 2009). The more minority individuals perceive provider discrimination and experience poor unsatisfying interaction, the less the minorities utilize health services even when needed (Brondolo et al., 2009; D'anna et al., 2010; Lee et al., 2009). For example, the participant in Bock (2012) narrative study reported that the physician who provided him with diabetes diagnosis at the age of 40 informed him that he was going to die from complications of the disease because the participant's family typically died from diabetes complications. The participant stated that he got depressed following the prognosis, and it became very difficult for him to figure out how to take care of himself for two and a half to three weeks. The participant had to turn to people with diabetes for help rather than the healthcare system. Bock (2012) study participant was a smoker, and the doctor who had passed the death sentence onto him recommended for him to continue smoking cigar two to three times a month. The participant learned not to smoke and not to be around people who smoke when he started investigating how to take care of himself through connecting with people with diabetes. This finding is consistence with other research findings that indicates that provider discrimination prevent minorities from

following physician's recommendations, which can lead to poor health outcome of the minorities (Brondolo et al., 2009; D'Anna et al., 2010).

The link between perceived discrimination in receiving healthcare and racial/ethnic disparities in self-rated health status, physical, and emotional functional limitation; and assessed whether the effects of discrimination varied by racial/ethnic group and gender have been investigated (D'Anna et al., 2010). The researchers analyzed data from the 2001 California Health Interview Survey Adult File (CHI 2001) of a sample of 55, 428 participants. The results showed that the minority population in the study had poorer health than the non-Hispanic Whites based on the self-rated report. The participants who reported experiences of discrimination when receiving healthcare in the past attributed the cause of discrimination to their race, ethnicity, language, or accent (D'Anna et al., 2010). The findings from the study revealed that recent experiences of racial, ethnic, language, and accent discriminations in the health care settings were associated with the negative effect on health and increase physical and emotional health limitations. The findings corroborate with other existing research that have noted negative association between individual perception and discrimination that are directed to a certain group and various qualities of health status (Brondolo et al., 2009; Ford & Airhihenbuwa 2010; Lee et al., 2009; Quinn et al., 2011).

Minorities reports being judged unfairly or being treated disrespectfully by their medical providers because of their racial/ethnic background, language barrier, the type of health insurance, and lack of funds to pay for the care (Brondolo et al., 2009; D'Anna et al., 2010; Ford & Airhihenbuwa 2010; Lee et al., 2009; Quinn et al., 2011). Individuals

with diabetes require a great deal of medical follow-up (Marshall, 2005). However, research has shown that individuals who have negative experiences in healthcare facility are less likely to continue to seek medical services, even if the individual has a need to seek health care services (Lee et al., 2009). Lee et al., (2009) conducted a study through analyzing data from 2001 survey on Disparities in Quality of Health Care, which was sponsored by the Commonwealth Fund. The researchers investigated the association between perceived provider discrimination, healthcare utilization, and health status in racial and ethnic minorities to expand the understanding of how discrimination affects health disparities. African Americans, Asians, and Hispanic reported significantly more perceived provider discrimination than non-Hispanic Whites. African Americans reported greatest perceived discrimination when compared to non-Hispanic Whites. Hispanics and Asians reported having more unsatisfying health care provider interaction. The African Americans in the study did not have significantly more unsatisfying interactions with Healthcare providers than non-Hispanic Whites. The individuals who reported having had provider discrimination and negative experience within a healthcare setting were less likely to use health care services even when they needed the medical services as compared to individual with no negative experiences. Unsatisfying interaction with physicians and perceived provider discrimination positively affected having unmet needs for healthcare utilization. However, the effect of perceived provider discrimination on unmet need for health care use was nearly twice as strong as that of having unsatisfying interaction with a physician. The unmet need for health care utilization directly influenced the poor health status of the participants. The study finding indicated that the

association between racial/ethnic minorities and poor physical health is mediated by perceived health care provider discrimination. In other words, African Americans poor health status is mediated by perceived health care provider discrimination. Lee et al., (2009) findings were consistent with literature reflecting that negative experiences under medical provider's care creates additional vulnerabilities in an already vulnerable minority population, and act as one means of creating and supporting health disparities in African Americans and Hispanics (Brondolo et al., 2009; Ford & Airhihenbuwa 2010; Quinn et al., 2011).

Historical and everyday racism that minority experiences have been linked to racial/ethnic health disparities (Krieger, 2008; Mays et al., 2007). Krieger (2008) examined the role that racism play in racial/ethnic health disparities based on previous studies, and reported that individuals' biology is unfavorably affected by the harmful physical and psychological exposures that result from racism. Racism shape exposure and vulnerability to economic and social deprivation (D'Anna et al., 2010). Other researchers have reported that racism shape socially inflicted trauma that are directly experienced or witnessed and create direct inadequate or degrading medical care (Hicken, Gee, Morenoff, Connell, & Snow, 2012; House, 2001). Krieger (2008) noted that the poor health of African Americans relative to White population resulted from White privileges enforced through slavery that was legal racism plus individuals live in a world of racialized class relations and class contingent race relations. In other words, racial/ethnic inequalities are shaped and fostered by class inequalities and class inequalities are shaped and fostered by race/ethnic inequalities.

## **Self-Care Behavioral Factors**

Diabetes self-care management involve checking foot for sores, controlling glucose level, and complying with physicians prescribed diet, physical activities, and medication regimen (Hawkins, Watkins, Kieffer, Spencer, & Espitia, 2015). Type 2 Diabetes Mellitus is a complicated disease to manage because most of the care and treatment involve behavioral self-management (Chlebowy, Hood & Lajoie, 2010). A large rapidly growing literature suggests that African Americans are significantly less likely to adhere to self-management recommendations compared to non-Hispanic Whites, accounting for higher complications and mortality rates among African Americans (Chlebowy et al., 2010; Gumb, 2012; Schulz et al., 2005; Marshall, 2005; Shenolikar, Balkrishnan, Camacho, Whitmire, & Anderson, 2006). Medication adherence is influenced by socioeconomic factors and an individual's knowledge, beliefs, attitudes, perception of the disease severity, and expectation from treatment (Bock, 2012; Shenolikar et al., 2006).

Shenolikar et al., (2006) completed a study on the association between race and medication adherence among type 2 diabetes patients. This was a longitudinal study conducted by using patient data from North Carolina Medicaid program. The three categories of the race of the participants were Whites, African Americans, and other race. Medication adherence was measured by collecting information from the pharmacies when the participants refilled their prescribed medications. The pattern of prescriptionrefill was used as a measurement of adherence under the assumption that the patients took the filled prescription. The number of days an individual was in the hospital was subtracted because any medication taken during hospitalization period was issued by the hospital and was entered in the pharmacy record. The Whites had a significantly higher prescription refill and higher medications consumption in the two years than African Americans and other races. Other races and Whites had significantly higher number of comorbidities as compared to African Americans. White patients' adherence to medications was significantly higher than African Americans patients' adherence to anti-diabetic medication. However, Chlebowy (2010) noted that African Americans are faced with medication adherence due to barriers such insufficient education and treatment affordability.

Researchers reports that external factors facilitate African Americans type 2 diabetes management behaviors, and the internal factors serve as barriers to African Americans self-management. For instance, Chlebowy (2010) completed a mixed method study to identify facilitators and barriers to self-management of Type 2 diabetes mellitus. The participants were 38 African Americans adults with type 2 diabetes who received care at health care agencies in the Southeastern United States. Quantitative data was obtained using survey questions that included duration of Type 2 diabetes, use of medication to manage diabetes, history of other chronic illnesses, and demographic data. Focus group was used to obtain qualitative data to identify facilitators and barriers to selfmanagement of Type 2 diabetes. The external factors such as support from peers, families and healthcare providers influenced the participants' adherence behaviors. The participants reported that health care providers did not provide reinforcement or encouragement, but were the source of information. The families provided support by administering and prompting the participants to take their medications. The participants gained knowledge about diabetes through their diabetes peers, seeking information themselves and health care provider. The diabetes peers provided the major source of reinforcement for self-management behaviors as reported by the participants. The internal factors such as fears of glucose monitoring, lack of control over dietary lifestyle, memory failure, and perceived lack of control over diabetes were described as the barriers of adherence. The participants reported having difficulties following dietary recommendation in social contexts such as family gathering and holiday celebrations. Several participants reported testing their glucose level only when they experienced diabetes symptoms such as dizziness and shaking. These participants reported fear of pain associated with glucose monitoring citing infrequent monitoring to avoid sore fingers. A great number of the participants indicated that they failed to test their glucose levels regularly and to take their medications because of being forgetful. These participants also reported forgetting to eat regularly and remembered to eat only when they experienced diabetes symptoms. The study showed that barriers to self-management of diabetes type 2 are perceived by African Americans to be outside of their personal control.

Other researchers have asserted that individual's attitude and behavior influences the individual's health outcome citing that almost fifty percent of all US deaths are linked to unhealthy habits including sedentary lifestyle, smoking, and alcohol abuse (Gumbs, 2012; Wu & Schimmele, 2005). For instance, Alijasem, Peyrot, Wissow, and Rubin (2001) study that examined the relationship barriers to diabetes treatment and selfefficacy with self-care behavior revealed that self-perceived capability to carry out a behavior is linked to treatment compliance. Alijasem et al., (2001) completed a study of 309 participants with type 2 diabetes. The participants self-reported physical activities, diet, how often they tested their blood glucose level and skipped taking medications, and whether they adjusted insulin and diet to correct or avoid high blood sugar. The participants were also asked to report perceived barriers to their self-care behaviors. Individuals who reported perceived barriers to carrying out self-care behavior had worse exercise behaviors and poor diet. The participants who had great self-efficacy tested their blood glucose level frequently, adhered to frequency of their medication regimen, and had less frequent binge eating.

The differences in cultural practices within the diverse cultures in the US show racial ethnic health disparities corresponding differences in health behaviors (Dareden et al., 2010; Najman et al., 2006; Wu & Schimmele (2005). According to Gumbs (2012), African Americans with diabetes find self-care challenging because of the complexity of the daily regimen requiring them to make lifestyle changes. The lifestyle changes pertain to blood glucose level monitoring, exercise, diet, medication management, and stress management. The commonly behavioral factors and lifestyle that have been linked to high morbidity and mortality are smoking, lack of exercise, alcohol and drug abuse, poor nutrition habits and high risk sex (Shneiderman et al., 2001; Wu & Schimmele, 2005). Other researchers have cited noncompliance to treatment regimen (Bertera, 2003) and not seeking medical services in a timely manner (Smith et al., 2011; and Quinn et al., 2011) as behavioral factors that are linked to chronic health complications.

Unhealthy behaviors are linked to medical conditions such as Diabetes, stroke, HIV/AIDS, heart disease, cancer, and tuberculosis through unhealthy behaviors (Khang, 2010; Shneiderman et al., 2001; Smith et al., 2011). For instance, Khang (2010) used a national longitudinal survey data to study the risk factors related to development of chronic health conditions such as diabetes, cancer, heart disease, hypertension, and stroke progression on race, body mass index and socioeconomic status. The minorities in the study had unhealthy diet and negative health behaviors, which subsequently led to obesity and chronic health issues such as diabetes. However, other researchers have asserted that minorities may lead sedentary lifestyles and have unhealthy diet because of lack of a supportive physical environment that can provide opportunities for physical activities and healthy diet (Lawrence, Hazlett, & Hightower, 2010; Najman et al., 2006; Robert, 1999; Shneiderman et al., 2001).

## **Socioeconomic Status and Environmental Factors**

Socioeconomic status of individuals and the environment in which the individuals live and works have been linked to racial ethnic health disparities (D'anne et al., 2010; Lowcook, et al., 2012). Health researchers and social scientists have developed increasing interest in studying the interaction between social disadvantage and environmental health, and how they contribute to racial ethnic health disparities (Cohen, et al., 2010; Connolly, Unwin, Shrriff, & Kelly, 200; Darden et al., 2010; Davis et al., 2005; Hicken, Gee, Morenoff, Connell, & Snow, 2012; Najman et al., 2006; YinusaNyahkoon et al., 2010). For example, Connolly et al., (2000) study showed a significant relationship between Type 2 diabetes and SES, which was mostly marked between the ages of 40-69. Connolly et al., (2010) completed a study of the association between diabetes prevalence and SES. The researchers obtained patients information from a community-based diabetes register. The data was also collected from the hospital diabetes register. The data obtained from health care facilities included gender, age at diabetes diagnosis, current diabetes treatment, and address. The variables used to score for deprivation SES were the proportion of male unemployed, manual workers, one parent household, self-reported chronic health, pension income and living alone, no household car, overcrowded household, and living in rented property. The prevalence of Type 2 diabetes in the least deprived quintile was 13.4 per 1000 population compared with 17.2 per 1000 population in the most deprived. Patients aged between 40-69 years old had the highest prevalence of type 2 diabetes. The steepest gradient of the prevalence of Type 2 diabetes across deprivation quintile among individuals of 40-69 years old, were due to increase exposure to lifestyle and environmental risk factors for Type 2 diabetes.

Social and economic inequalities are determinants of racial/ethnic health disparities (Babey et al., 2010; Braveman et al., 2010; D'Anna et al., 2010; Hargreaves et al., 2011; Kahng, 2010; Lowcock et al., 2012; Wu & Schimmel, 2005). SES refers to the broad range of socioeconomic circumstances such as income, occupation, education, and level of the asset or wealth in which individuals are hierarchically stratified (D'Anna et al., 2010; Robert, 1999). Hargreaves et al., (2011) pointed out that social stratification results into unequal distribution of social determinants of health such as material living conditions and psychosocial circumstances including behavioral and biological risk experienced by minorities. The minority individuals with medical symptoms of any health issue often face significant economic and social barriers that make them delay seeking medical attention in which appropriate diagnosis might be made (Brondolo et al., 2009; Hargreaves et al., 2011; Lowcock et al., 2012). The participants on Hargreaves et al., (2011) study of social determinants of tuberculosis reported key determinants of tuberculosis to be financial geographic barriers to health care access, difficulties in transport to health facilities, food insecurity and malnutrition, poor environment and housing condition, and lack of support to seek medical care when they felt sick.

Neighborhood environment influences an individual's diet and physical activity through the availability of recreational facilities, educational resources, grocery stores, and through neighborhood social environment (Krishnan et al., 2010). Studies indicate that the socioeconomic characteristics of a neighborhood may affect health status independent of an individual SES (Krishnan et al., 2010; Najman et al., 2006). For instance, Krishnan et al., (2010) completed a study on the association between individual and neighborhood SES and type 2 diabetes rates among African American women. Two hundred and twenty seven participants were obtained from the prospective Black Women's Health study. Women in the study had completed biennial questionnaires that were mailed to them since 1995. The neighborhood SES was measured using the characteristics of the US Census block group. The study excluded women who already had diabetes, gestational diabetes, cardiovascular disease or cancer. The family history of diabetes, vigorous physical activity, smoking status, alcohol use, weight, and height were part of the baseline questionnaire, which were updated on biennial follow-up questionnaire. Physical activity was assessed by asking the participants how many hours per week they spent in activities such as swimming, running, basketball and aerobics. Neighborhood SES was updated every two years, and the changes were made to the value of neighborhood SES if a woman's new residence was classified in a different quintile than her previous address. Physicians provided the data from the participants' medical records. Of the 227 participants, 218 (96%) received the diagnosis of type 2 diabetes, 2 had type 2 diabetes, 2 had gestational diabetes, 3 did not have diabetes, and 1 had metabolic syndrome. Neighborhood SES was linked with diabetes incidence among the women who had more than high school education. The researchers observed the association between neighborhood SES with diabetes among women who were in the highest income category. The study showed that both neighborhood SES and individual play a role in the development of diabetes in African American women. The lower level of neighborhood SES and the lower level of individual SES were independently associated with an increase linked to Type 2 diabetes. The women with the most income and education had higher risk of diabetes association with neighborhood SES. This finding is consistence with other research findings that indicates that the neighborhood SES influences an individual's health despite the individual's SES (D'Anna et al., 2010; Robert, 1999).

Physical activity is one of the most neglected behavioral treatment regimen of Type 2 diabetes (Dutton, Johnson, Whitehead, Bodenlos, & Brantley, 2005). Researchers assert that environmental barriers may play a role in African Americans lack of physical activities (Connolly, Unwin, Sherriff & Kelly, 200; Dutton et al., 2005; Krishnan, Cozier, Rosenberg, & Palmer, 2010). Low socioeconomic neighborhoods have no to poor quality municipal facilities such as bicycle paths, walking paths, and exercise and recreation facilities in a public location that can facilitate physical activities (Najman et al., 2006). Dutton et al., (2005) completed a study on barriers to physical activity among predominantly low-income African American patients with Type 2 diabetes. The participants were 105 adults with Type 2 diabetes attending primary care appointments. Demographic and diabetes questionnaire were administered to the participants. The participants were asked to rate the frequency in which they experienced perceived barriers to physical activities on a scale of 1 (never) to 6 (always true). The researchers performed a review of the participants' medical charts for glucose levels, weight, blood pressure and height. When asked how important the participants believed exercise assisted with controlling diabetes; 75% reported that exercise is extremely important, 18% reported important, 5% reported moderately important, and 2% reported slightly or not important. When asked if exercise would prevent future complications from participants' diabetes; 60% reported it was most likely, 17% reported likely, 10% reported moderate likely, 8% reported unlikely, 5% reported very unlikely. Commonly reported barriers to exercising were lack of access to exercise facility and equipment, lack of physician advise, lack of time, lack of social support, weather, health problems, and caring for a child.

The individuals who lead sedentary lifestyle have higher chances of developing chronic health issues such as diabetes and obesity as compared to individuals who

participate in regular physical activities (Lawrence et al., 2010). Researchers asserts that behaviors and dietary lifestyle affects individuals' health, but environmental and social circumstances deprive African Americans a from living healthy lifestyle, which put them at a disadvantage of health and disease (D'Anna, et al., 2010; Ford & Airhihenbuwa, 2010; Kahng, 2010; Quinn et al., 2011). According to Lawrence et al., (2010) the neighborhoods and the communities with low income have high crime rates making it less safe for the residents to spend time outdoors and to engage in physical activities.

The characteristic of the neighborhood where individuals resides has been linked to the difference in quality of life (Darden et al., 2010; and Frohlich et al., 2002). Some neighborhoods do have characteristics that enhance the quality of life of the residents while others neighborhoods are harmful to the residents (Darden et al., 2010). The neighborhood effect is one of the concepts that emerged from the literature review for this study. Darden et al., (2010) research on neighborhood effect presented quantitative data that revealed that poor neighborhoods have poor housing quality, limited job opportunities, limited grocery store, and lack other shopping facilities, which put the residents at a disadvantage as compared to residents of more affluent neighborhood. Bayer and McMillan (2005) asserted that non-White neighborhood predominantly experience poor quality and quantity or resources. For example, Krishnan et al., (2010) noted that poor urban areas that have higher proportion of African American residents have high ratio of fast food restaurant to regular full-service restaurants.

Krishnan et al., (2010) examined the relationship of restaurant meal consumption in the incidence of type 2 diabetes among African American. The study data was obtained from the prospective Black Women's Health Study, which began in 1995 and is an ongoing study. This study analyzed data from 1995 to 2005. The research excluded women who at baseline had the history of diabetes, gestational diabetes, cancer, who were pregnant, and who had not provided data on their weight or height at baseline. The women who did not answer the questions on the use of restaurant meals were excluded as well. The demographic, physical activity, usual diet, medical and reproductive history, height, weight, and the use of alcohol and cigarette were collected on the baseline questionnaire. The information was updated biennially. Follow up questions inquired about new diabetes diagnoses in the past two years. The accuracy of Self-reported diabetes was assessed from the patients' medical records that were provided by their physicians. The food frequency questionnaire contained foods that are commonly consumed by African American women. The participants were asked to check how often they had eaten the food in the past year and the serving size. The individuals in the study were also asked how often they had breakfast, lunch and dinner or ordered food from the restaurants. In regards to restaurant food, the participants were asked to provide a separate response as to how often they ordered fried chicken, hamburgers, chines food, fried fish, pizza, and Mexican food. The dietary questionnaire response varied from "never in the past year" to "about every day." The most often restaurant food eaten per week was hamburgers, 18% followed by fried chicken, 13%. By 2001, hamburgers continued to be the most commonly consumed restaurant food, and food from Mexican restaurant consumption increased by 5%. The participants who consumed fried chicken, hamburgers, and fried fish consistently had a lower level of education attainment and

poor health behaviors such as less physical activities and smoking. The mean Body Mass Index (BMI) of the women who had high frequency of fast food restaurant meals were markedly higher than those in low category frequency 2.2 for hamburgers, 2.9 for fried chicken, and 1.9 for fried fish. The researchers identified 2873 incident cases of type 2 Diabetes during ten years follow-up. Krishnan et al., (2010) study found positive relationship between frequent consumption of fast food restaurant meal and Type 2 Diabetes, which was stronger for hamburgers and fried chicken, but weaker for Chinese food and fried fish. Mexican food and pizza were not associated with risk for diabetes. This finding is consistent with other studies that revealed that fast food restaurants serving the least healthy foods are predominantly in African Americans neighborhood (Lewis, Sloane, Nascimento, Diament, & Guinyard, 2005; Morland, Wing, Diez, & Poole, 2002; Powell, Chaloupka, & Bao, 2007).

The association between ecological factors and the onset of medical problems have been studied (Lewis et al., 2007; Lowcock et al., 2012; Morland et al., 2002; Powell et al., 2007; Yinusa-Nyahkoon et al., 2010 ). Such studies have shown that predominantly African American neighborhoods have a disproportionate number of fast food restaurants, fewer grocery stores, and less high-quality food (Lewis et al., 2007; Morland et al., 2002; Powell et al., 2007). For example, Lewis et al., (2007) examined the availability and food options at restaurants in a less affluent neighborhood and more affluent areas of Los Angeles. The study compared the residents access to healthy meals purchased in restaurants and meals prepared at home. The surveyors assessed 659 restaurants of which 348 were located in the targeted area with a high proportion of African Americans (35%) and 311 in comparison area with fewer African Americans (7.8%). The four noncontiguous targeted areas were located in South Los Angeles, Inglewood, and North Long Beach, while West Los Angeles was the comparison area. Each city's environmental health office electronic database provided the surveyors with the list of restaurants. The surveyors consisted of five community organizations and students studying Master of Planning Program in USC. Restaurants were categorized as fast food, fast casual for foods that were prepared post placing orders, and sit down dining. The surveyors reported having difficulties to achieve the desired categories because of lack of sit down restaurants within some targeted areas. Inventory of healthy food option was obtained from restaurant survey. The survey instrument used the restaurants' menu as a source of information to collect information about the type of food offered at a restaurant, healthy food preparation, and if the customers had options to request a health alternative. Included in the survey instrument were also questions about meal prices, beverage options and restaurants characteristics, such as cleanliness, public transportation, and parking access. The targeted area had 25.6% fast food restaurants, which was significantly higher than the comparison areas that had 11.2%. Comparison area had 58% full-service restaurants as compared to 27% restaurants in targeted area. Nine percent of restaurants in comparison area made it easier for customers to find items by labeling the foods and providing nutritional information compared with 6.5% of the restaurants in targeted areas. In terms of food preparation, 40% of restaurants in comparison areas provided meals with five or more healthy preparation choices as compared to 27% of the targeted area restaurants. Forty-two percent of restaurants in

comparison area provided 5 or more healthy options such as green salad, cooked vegetables, baked potatoes, brown rice, fresh fruits and vegetable entrees as compared to 36% restaurants in the targeted area. In terms of the restaurant environment, the targeted area restaurants were significantly less likely to receive high marks than restaurants in comparison areas. Less than 5% of restaurants in targeted area received an excellent review for the environmental characteristics. The research showed that the physical availability of healthy foods influences individuals' diets. According to Moraland et al., (2002), the disparities in access to healthy quality food that exists in different neighborhoods places racial minorities at a higher risk of diseases.

Physical availability of food have been studied in order to understand individuals' inability to change dietary habit despite physician recommendation. For instance, Morland et al., (2002) completed a study of the distribution of food stores and food service places by racial segregation and neighborhood SES in Minnesota, Mississippi, North Carolina, and Maryland. The researchers obtained the names and addresses of food places from the departments of health and agriculture. The median house hold value was used to estimate neighborhood SES. The neighborhood racial segregation was measured using the proportion of African Americans residents. The high SES neighborhoods had large numbers of supermarkets and gas stations with convenience stores. The White neighborhoods had four times more supermarkets as compared to the African Americans neighborhood. The study supported other study findings that have indicated that lack of access to supermarkets that offer wide variety of foods at decent prices, serves as a barrier to minorities such as African Americans diets (Powell et al., 2007; Satia, Galanko, & Siega-Riz, 2004). Such barriers make it difficult for African Americans with diabetes to achieve sustainable dietary changes that would affect risk for diabetes complications (Krishnan et al., 2010; Marshall, 2005; Tuchman, 2011).

Poverty, low education attainment, and residing in economically depressed environments all contribute to increased prevalence of poor health within African American communities (Brondolo et al., 2009; Hargreaves et al., 2011; Robert 1999; Quinn et al., 2011: Wu & Schimmele, 2005). According to Hargreaves et al., (2011) hunger, poverty, and malnutrition, may increase susceptibility to infectious diseases such as tuberculosis, and severity of clinical outcome. Poverty striven individuals have difficulties investing in health, nutrition, and education of their children, which leads to future lower wages in life and thus sustain intergenerational cycles of poverty (D'Anna et al., 2010; Hargreaves et al., (2011). Poverty inform of material deprivation includes dirty water, poor nutrition, and lack of quality medical care that account for the tragically short lives of African Americans (Marmot, 2005). According to Vanroelen et al., (2010), high mental and emotional demands of work and low control over the work environment are associated with a number of physical and psychological health outcomes of minorities. In the United States, African Americans are overrepresented among the poor. According to Wu and Schimmele (2005), African Americans have a poverty rate three times higher than Whites, and thus multiple health risk among African American population because of the link between SES and health outcome.

Social determinants of health are associated with chronic health issues and health behaviors (D'Anna et al., 2010; Hargreaves et al., 2011; Khang, 2010; Lowcock et al.,

2012; Quinn et al., 2011; Wu & Schimmet, 2005). The disparities in social determinants of health are reflected in the degree of inclination of SES (Hargreaves et al., 2011; Lowcock et al., 2012), which is linked to health inequalities (Lowcock et al., 2012). According to Lowcock et al., (2012), minorities in the US experience poor health outcome and have low life expectancy as compared with advantaged majority because minorities are in the lower end of SES and lower level of education attainment (Lowcock et al., 2012).

In order to examine the link between social determinants of health and racial/ethnic health disparities, some researchers have turned to education attainment (Baker, Leon, Greenaway, Collins, & Movit, 2011; Egerter et al., 2011). In the United States, 50% of Asians and 31% of non-Hispanic White adults have College degree as compared to 17% of African Americans. Individuals with more education are likely to live longer, and experience better health outcome because of practicing health promoting behaviors such as consuming healthy diet, participating in regular exercises, having well healthcare visits and screening, and seeking medical attention in a timely fashion (Baker et al., 2011; Egerter et al., 2011). Egerter et al., (2011) explored the pathways in which education achievement influence health by analyzing previous research. The researchers reported that individuals with higher education attainment were able to make betterinformed choices regarding obtaining and managing medical care and other health related options based on their increased knowledge, problem-solving, and coping skills. The individuals with greater education attainment reported increasing fruits and vegetables consumptions, refraining from smoking and alcohol use, and engaging in regular physical

activities as compared to individuals with lower education attainment. Higher education attainment was linked to living in health-promoting neighborhoods that are less stressful, have access to recreational facilities, and have grocery stores with healthy affordable foods. The individuals with higher education attainment had higher paying jobs that provided them with the necessary income to live in healthy neighborhoods that enabled them to maintain healthy behaviors. The adults with inadequate education attainment and health literacy rated their health as poor as compared to individuals with higher education attainment. The workers with less formal education were more likely to hold low-income jobs with more environmental hazards and poor working conditions. These individuals experienced psychosocial stress at work due to perceived discrimination and lack of social support among peers at the workplace. The psychosocial stress had impacts on the individuals' health. The research findings were consistent with the literature revealing that social determinants of health are linked to SES. For instance, Wu and Schimmele (2005) study revealed that low income and less education attainment were linked to limited access and utilization of health care services.

The stress that comes with the jobs that individuals of low social class have, impacts their health (Ayers & Kronenfeld, 2009; Khang, 2010; Najman et al., 2006; Vanroelen et al., 2010). The American Diabetes Association (2014.) noted that mental stress raises the blood sugar level in individuals with type 2 diabetes, which leads to diabetes complications. According to Vanroelen et al., (2010), the individuals with low SES often work in environments that are full of hazards resulting into injuries; often have no support from superiors at the job place; experience job insecurity; and the jobs are not flexible enough to enable the individuals to balance employment, family obligation, and maintain healthy behaviors. Such jobs can be detrimental to the individuals with diabetes due limited time to adhere to health care visits. According to Hawkins et al., (2015), Physicians often recommends for the individuals with diabetes to receive medical care from an interdisciplinary team of nurses, physicians, dietitians, and mental health professionals. In addition, the individuals with diabetes should have their blood glucose level tested by their physician every 3 months and have medical follow up with their physician every 6 months (Turner, Williams, Taichman, & Vijan, 2010). Vanroelen et al., (2010) noted that individuals with high SES have professional jobs, which offers them flex-time and flex places. Flex-time and flex-place provide the employees with opportunities to schedule well visits to their physicians as they are able to report to work on their own time or work from home. Working from home is essential when employees are sick because this could prevent the sick employee from stressful situations that could result into further medical complications (Vanroelen et al., 2010).

Numerous environmental hazards are associated with health issues of African Americans (Darden et al., 2010; Hicken et al., 2012; Najman et al., 2006; Yinusa-Nyahkoon et al., 2010). Using the National Health and Nutrition Examination Survey, for example, Hicken et al., (2012) found that there was an association between lead in the blood and increased blood pressure among African Americans, but not White adults. The African Americans of low SES had consistent blood lead and blood pressure, but not Whites of low SES. The study suggested that lead is associated with increased blood pressure and risk of hypertension among the disadvantaged population, which were
consistent with the literature reflecting that African Americans are disproportionately exposed to environmental hazards, putting them at risk of chronic health issues. Blood pressure is associated with diabetes complications (Bertera, 2003).

Hicken et al., (2012) examined the relationship between blood lead and blood pressure using data from the National Health and Nutrition Examination Survey of 2001 to 2008, which was administered by the Center for Disease Control and Prevention. The researchers examined the Diastolic (DBP), and pulse pressure (PP), systolic (SBP) blood pressure measures using average of at least three seated blood pressure readings. Hicken et al., (2012) used education attainment and family poverty income ratio as measures of SES. The study showed a relationship between blood lead and increase blood pressure for Blacks, but not White adults. This finding is consistent with growing literature on environmental health.

### **Research Justification**

In order to determine which research methodology to employ, the actual outcome of interest of this study was taken into consideration. A systematic review of literature on health disparities among racial ethnic health groups indicates that most research investigating racial ethnic health disparities are quantitative studies that obtained data from the existing database. Most of data in the existing database were collected through random digital dialing telephone survey. For example, Lee et al., (2009) used data from the 2001 survey on Disparities in Quality of life of Healthcare to examine the association between perceived provider discrimination, healthcare utilization and health status in racial and ethnic minorities. The measures used by the researchers included perceived provider discrimination and unsatisfying interactions with a doctor. The study made a contribution to the literature on perceived provider discrimination, which shaded some light on how racial ethnic health disparities are created and maintained, thus providing a means for future policy intervention.

Although the surveys include a variety of topics that are relevant to evaluating racial ethnic health disparities, the studies are cross-sectional, which makes predictors to be limited to one point in time. For instance, D'Anna et al., (2010) study was a secondary data analysis drawn from 2001 California Health Interview Survey adult file. The initial survey asked the respondents: demographic; socioeconomic position; self-reported physical and mental health status; physical health condition and medical care or advice; and health-related behaviors including diet, exercise, and alcohol use; access and healthcare utilization, and compliance to recommended tests; and health insurance coverage.

D'Anna et al., (2010) study and other survey research are self-reported health status through survey questions, which do not account for cultural differences in the interpretation of health and well-being. Self-reported health status is subjective and may not reflect individuals' functional health status. According to Wu and Schimmele (2005), health problems perspectives may be ethnically and culturally specific. In other words, ethnic and cultural groups may interpret health problems differently based on cultural beliefs and values. For SES, quantitative researchers use several variables to categorize the participants in groups such as low, medium, and high socioeconomic status, which may be artificial due to limited information and thus does not accurately describe an individual's true SES.

The inadequate amount of qualitative studies available in this domain is one of the reasons for this qualitative-phenomenological research on Racial/Ethnic Health Disparities. This researcher felt the fundamental need to fully understand the existence of racial/ethnic health disparities in the US from the view point of African American adults with health insurance coverage who have diabetes complications. What this researcher did not find in the literature review was a study that specifically interviewed minorities with health insurance coverage about their personal experiences with chronic health issue. By understanding the experiences of African American adults with chronic health problem, the findings will enhance the understanding of how racial ethnic health disparities are evolved and sustained, which will provide a concrete means for future policy intervention.

## **Summary of Literature Review**

This literature review chapter presented a number of prominent themes that were obtained from published literature. The phenomenological inquiry is designed for African American adults with diabetes complication to tell their stories, describe their experiences and to explain how they are coping with factors that contribute to racial/ethnic health disparities. Literature review explored social cognitive theory (Bandura, 1986) and Rosenstock (1966) health belief model as cited by Smith et al., (2011) in relation to how African American adults with chronic medical condition will describe their strategies for coping with the disease while battling factors that contribute to racial/ethnic health disparities.

Racial/ethnic minorities experience various health problems and poor health outcome than non-Hispanic Whites due to racism, socioeconomic risk factors, lifestyle behaviors, and environmental issues (Brondolo et al., 2009; D'Anna et al., 2010; Ford & Airhihenbuwa, 2010; Khang, 2010; Krieger, 2008; Quinn et al., 2011). The African Americans experience with inequalities in social, economic, environmental conditions deprives them opportunities for healthy behaviors (Hargreaves et al., 2011; Kahng, 2010; Kim et al., 2010; Robert, 1999). The social determinants of health influence African Americans' strategies for coping with diseases and determine their health outcome (Hargreaves et al., 2011). The literature review consistently showed that individuals are responsible for their own health (Kim et al., 2010; and Smith et al., 2011). Smith et al., (2011) posited that the poor health of minorities are as a result of poor life choices that some individuals make. According to Kim et al., (2010), America prioritizes medical care and individual behaviors as determinants of health. In the light of social determinants of health, racial/ethnic health disparities is difficult to mitigate by holding primary care physicians responsible for influencing individual patient to engage in behaviors that can prevent future illnesses. Although some researchers argue that health disparities are social injustice and that human services professionals have a moral imperative to ensure health equity (Hargreaves et al., 2011; Lowcock et al., 2012; and Kim et al., 2010), the literature did not reveal whether researchers have effectively communicated this ethical argument to the public and legislatures. The literature falls short in providing public health

professionals evidence based knowledge and in-depth understanding of intervention strategies for mitigating racial/ethnic health disparities.

The research aimed at filling a gap in the qualitative literature by exploring how African Americans with chronic health issues make meaning of their personal experiences. This hermeneutic phenomenological study gave African Americans adults with diabetes complications opportunity to express an authentic account of their experiences with diabetes in the context of racial/ethnic health disparities. By hearing personal experiences of African American adults with diabetes complication, the literature gap will be further mitigated. Chapter 3 provides a detailed explanation of hermeneutic phenomenological that will be used to explore the phenomenon.

#### Chapter 3: Research Method

The purpose of this phenomenological study was to describe the shared experiences, attitude, and perceptions of African American adults with chronic health issues and diabetes complications. I explored the participants' perceptions of racial/ethnic health disparities. Through the application of phenomenological approach, I collected each study participant's description of the phenomenon that will expand the field concerning how racial/ethnic minorities navigate ecological, social, and environmental barriers of health. In this chapter, I describe the study's research design and rationale for the design, methods of participant recruitment, criteria for participants' recruitment, ethical procedures used to safeguard all participants' information, data collection procedure, and my role as a researcher.

### **Research Design**

In this study, I employed a qualitative research design in the examination of African American adults with diabetes and their complications with the aim of expanding the understanding racial/ethnic health disparities. Qualitative researchers explore what a human or social problem means to individuals or groups (Creswell, 2009). In qualitative research, researchers seek to comprehend the experiences of a phenomenon or problem under study from the perspectives of research participants who have experienced the problem (Family Health International, 2012; Rudestam & Newton, 2007). The participants' perceptions and experiences, and the way the participants make sense of their personal experiences, are the focal point of qualitative research. Qualitative scholars investigate behavioral responses to human experiences (Creswell, 2009). In this study, I used a qualitative inquiry rather than a quantitative methodology to investigate, explain and describe behaviors, perceptions, attitudes, and experiences of African Americans adults with chronic health conditions and diabetes complications. According to Creswell (2007), unlike quantitative studies, qualitative researchers explore issues in order to provide a complex, detailed understanding of an issue. Quantitative researchers mainly emphasize statistical description and analysis of data to support a study conclusion (Creswell, 2009). The experiences of African Americans with diabetes may be difficult to record with existing quantitative measures, and these measures may not be sensitive to racial differences, SES, health behaviors, environment, and racism. For example, a researcher cannot measure how racism harms health, but can explore the ways in which varying levels and types of racism confer health risks.

The qualitative approach selected for this study was phenomenological research. Phenomenological research is a qualitative approach in which the researcher describes the meaning of individuals' personal experiences about phenomena or concepts as described by the individuals under study (Creswell, 2009; Smith, Flowers, & Larkin, 2009). When using phenomenology, researchers concentrate on describing what participants have in common as the participants experience a phenomenon (Smith et al., 2009). As a researcher, I used a phenomenological approach to seek information by collecting data, describing the data, and explaining the behavioral responses to the human experiences (Creswell, 2007). Rudestam and Newton (2007) asserted that the phenomenological approach requires the ability to look at things openly and define things as they are. The approach allowed the participants to reminisce and verbalize their memories of personal experiences of living with diabetes in the context of racial ethnic health disparities as noted by Smith et al., (2009).

Hermeneutical phenomenology was the phenomenological approach that was employed in this study. According to Creswell (2007), hermeneutical phenomenology research is grounded in the interpretation of participants' personal experiences. Hermeneutical phenomenology was selected because I sought to explore in-depth understanding of the personal experiences of African Americans with chronic health issues related to diabetes. The contexts or situations that have typically influenced or affected the participants' experiences of health disparities were explored. Accordingly, I reflexively interpreted the meaning of the personal experiences of the participants as noted by Creswell, (2009).

# **Rationale for Research Design**

Hermeneutical phenomenological qualitative approach was selected for this study because of its descriptive approach to gathering data and interpretive approach when explaining the experiences of the participants from their point of view (Creswell, 2007). The interpretive approach involves collecting data through interviews and diaries (Creswell, 2009). Therefore, face-to-face individual interviews were conducted to explore the personal experiences of African American adults with diabetes. The research design generated an in-depth understanding of racial ethnic health disparities as experienced by African American adults with diabetes because of the ability of phenomenological studies to produce rich, holistic, and complex data that provides thick, vivid descriptions that are nested in real context (Miles & Huber, 1994). Other qualitative approaches that focus on personal experiences include grounded theory, narratives, ethnography, and case studies. The goal of the phenomenological approach was to explain what the experience means for the individuals who have had the experiences and are able to provide a comprehensive description of the experience (Patton, 2002). The phenomenological approach was an appropriate framework to guide the research because I aimed at exploring the personal experiences of African American adults with chronic health condition related to diabetes with the goal of adding to the knowledge of racial ethnic health disparities.

Grounded theory method was developed by Glaser and Strauss in 1967 (Creswell, 2007). Creswell noted that the grounded theory was developed based on the notion that theories used in research are often inappropriate and not suitable for participants under study. Grounded theorists focus on developing or modifying a theory to explain a process, actions, or interactions that are grounded on the participants' perspectives (Creswell, 2009). The theory is developed from the raw data obtained from the participants who have personally experienced the phenomenon. Grounded theory was not suitable for the current study in spite its naturalistic and interpretive nature because I did not intend to create or modify theories. According to Creswell (2007), the grounded theory design is best used when a theory is not available for explaining the process; therefore, the current study did not require grounded theory design. I employed the existing SCT and the HBM. Furthermore, grounded theory data collection begins with a large number of participants and several in-depth interviews, which can be time

consuming for a researcher with limited resources (Creswell, 2007). In other words, I used theoretical frameworks that already exist and worked well with my study.

Ethnography is a qualitative research design that takes place in a natural setting whereby the researcher studies a group associated with culture (Creswell, 2007). The researcher studies the cultural descriptions of behaviors, perceptions, and social interactions that occur within the particular group over a long period of time. In ethnography, the researcher observes and interviews members of the cultural group by themselves immersing in the day-to-day lives of the cultural sharing group (Creswell, 2007). Ethnographers use the theory that states that a culture develops when a group of individuals interact together for a period of time (Patton, 2002). Creswell (2007) documented that ethnography is mostly used by cultural anthropologists. The anthropologists focus on an entire cultural group who resides in the same area, interacts frequently, and shares patterns of behaviors and beliefs. The ethnography approach is inappropriate for this research because I sought to explore personal life experiences of African Americans with diabetes complications. Moreover, ethnography would require me to spend an extensive time in the natural setting of the research participants.

Case studies are a qualitative approach in which the researcher does an intensive description and analysis of a single or more individuals, a program, an event, an activity, or a process (Creswell, 2009). Creswell (2007) defined a cases study as an approach in which the researcher explores a case or multiple cases over a period of time through collecting detailed, in-depth data using multiple sources of information. Researchers who use a case study method obtain their data from several sources, including naturalistic

observation, interviews, archival records, and audiovisual materials and provide reports on a case description and case-based themes (Creswell, 2007). In this study, I obtained data from only interviews as opposed to other sources. Although case studies provide a rich source of information about individuals or programs and insights into possible causes of individuals' behaviors or program, the approach was not a good fit for this study. The case study would not provide answers to the core research question: What is it like to be African American with a chronic medical condition associated with diabetes complications? Furthermore, the approach requires time, funds, and tasking for a single researcher with limited resources.

The final qualitative paradigm that focuses on lived experience is the narrative approach. In narrative inquiry, the participants tell their stories (Creswell, 2009). The researcher then interprets those stories and attempts to find meaning in those stories. In the narrative approach, the scholar focuses on studying and gathering data through the collection of individuals' stories, reporting the experiences of the individuals, and chronologically ordering the meaning of those experiences reported by the individuals (Creswell, 2007). The researcher uses the information from the individuals to retell the individuals' stories. For the purpose of studying African Americans with diabetes complications, narrative is not preferred because the approach focuses on telling stories of participants. The purpose of this study was to present the participants' personal experiences as they relate to racial ethnic health disparities.

## **Role of the Researcher**

Because this study was primarily qualitative, I was the investigator and primary instrument for data collections and analysis (Patton, 2002). I collected the data through a series of face-to-face and telephone interviews. I then transcribed, analyzed, and reported the data. I engaged the participants through the interview questions to explore the personal experiences of African Americans adults with diabetes complications.

A face-to-face interview enables researchers to probe the participants and to clarify unclear questions to the participants (Shaughnessy & Zechmeister, 2006). Accordingly, I followed up incomplete or ambiguous answers to open-ended questions. After the interviews, I interpreted the data gathered and made recommendations for social change. The participants' account of the phenomenon, were interpreted and translated into a coherent explanation of their encounter.

### **Research Questions**

Qualitative researchers state research questions that consist of two forms, which are central questions and secondary questions also known as subquestions (Creswell, 2009). According to Creswell, the two forms of research questions in phenomenological studies are designed to gather data that lead to textural and structural description of the participants' experiences. The central question is used to explore the central phenomenon while the secondary direct the interview protocol (Miles & Huberman, 1994). This phenomenological study contained one central question involving what the participants experienced in terms of the phenomenon and the context that frame each participant's experience related there in (Miles & Huber, 1994).

#### **Central Research Question**

What is it like for African Americans adults with chronic illnesses associated with diabetes navigating factors that contribute to racial ethnic health disparities?

# **Secondary Research Questions**

- 1. What are the factors affecting the lives of African American adults with chronic illnesses associated with diabetes complications?
- 2. How do the experiences of African American adults with diabetes complications affect their health behaviors?
- 3. How does African Americans adults with chronic illnesses cope with the diabetes complications diagnosis in regards to their environment?
- 4. What strategies do African American adults with diabetes complications use to cope with their diagnoses and to adhere to health care providers recommendations?

# Methodology

The participants in this study were African American adults with diabetes complications residing in the New York State Hudson Valley region, which includes Orange County, Rockland, Westchester county, and Dutches County. Orange and Dutches counties were selected because of the large number of African American residing in the counties. Poughkeepsie city was the main focus in Dutches County because of the large number of African American residing in the city. According to U.S. Census of Bureau (2010), 33.5% of the Poughkeepsie population is African Americans. Newburg and Middletown cities were the main research location in Orange County because Newburg has 30.2% African Americans, and Middletown has 21.0% African Americans (U.S. Census Bureau, 2010). The percentage number of African Americans in these counties provided me with idea of locations for the study flyer dissemination. The rates for diseases are higher in the minority than majority in Orange County, and diabetes mortality rate in the county was above Hudson Valley region and New York State in 2004-2006 (Hudson etal.,2013). Between 2005 and 2007, 181 deaths were due to diabetes mellitus, and 2,065 deaths were due to diseases of the heart (Hudson et al., 2013).

The study participants were selected through purpose sampling. Purpose sampling was selected because I aimed at obtaining in-depth information about racial ethnic health disparities from African American adults as the participants describe their experiences with diabetes. According to Miles and Huberman (1994), qualitative researchers use purpose sampling rather than random sampling in order to obtain information-rich cases. Parton (2002) noted that purpose sampling yields insights and an in-depth understanding of the issue under study. Use of purpose sampling allowed me to get reach understanding of racial ethnic health disparities through interviewing the participants who are experiencing the phenomenon.

### **Recruitment Criteria**

The criteria for recruiting, screening, and selecting participants for this study was as follows: (a) must be African American adult at least 18 years of age, (b) must have diabetes with complications, (c) must have had some type of health insurance at the time of diabetes diagnosis, and (d) must live in Hudson Valley Region in New York. In this study, I targeted at least six to eight participants, which were obtained through various recruitment efforts. Although the sample size of the participants in this study was small, Patton (2002) clarified that the small sample size is most suitable for homogenous research study participants. Miles and Huberman (1994) recommended small sample size in phenomenological studies because the approach focuses on the perspective rather than the population. Large data will yield repetitive information, which would eventually be redundant (Mason, 2010). However, the sample size may change if the information that emerges from the open-ended question indicates the value of a change, and add it to the sample during the study. Suri (2010) stated that open-ended questions produce a new report and every new report offers additional information. Patton (2002) documented that the sample size should be flexible and emergent. Only six participants were interviewed because the information was maximized. The information obtained from the six participants became redundant, which led to the termination of the interviews.

The participants were recruited via electronic flyers, which were posted on Face book. Paper flyers were also disseminated in local clinics, endocrinologists' offices, hair and nail salons, barber shops, and churches that are frequented by African Americans. My contact information was provided for those interested in the study.

Telephone questionnaire was used to screen callers in order to determine whether the callers met the study's criteria. Inclusion criteria included (a) self-identification as African American adult, (b) has diabetes with complications, (c) has some type of health insurance, and (d) reside in Hudson Valley Region in New York. I intended to offer detailed letters explaining participation in the study through electronic mail or postal services, but none of the participants were willing to provide their addresses or electronic mail address. Participants were contacted via phone to set up the interview. Because the participation was limited to African American adults with diabetes complications, indepth data collection was used to provide the opportunity to reach saturation.

# **Data Collection Procedure**

The researcher is an essential instrument in the data collection process in qualitative studies (Creswell, 2007 & Patton, 2002). The data collection instrument consisted of eleven interview questions created based on literature review. I used open-ended semi-structured in-depth, face to face interview process that included few closed questions to get better understanding of the experiences, and the perspectives of the participants. The in-depth interview explored each study participant's experiences, attitudes, and perspectives about racial ethnic/health disparities.

The interviews were scheduled based on the participants' availability, and were conducted in public places; Park, Dunkin Donuts, KFC restaurant, and at a shopping mall in Hudson Valley Region in New York. The participants selected a convenient date, time and place from the proposed list of locations of where semi-structured interview took place. Before interviews were conducted, I obtained the informed consent from the participants. The informed consent assisted me to identify if the research participants have the capacity to consent to the research. I made the participants aware of the voluntary nature of the participation and I freely expressed consent without undue influence as recommended by Frank-Nachmias and Nachmias (2007). I provided the

participants with information concerning participation in the research that reasonably might affect the participants' willingness to participate including limits of confidentiality and monetary or other costs or reimbursements. The research procedure was clearly described to the participants. The participants were informed about the purpose of the research, expected duration, and procedures. I informed the participants of the right to decline to participate and to withdraw from the research once the participants had begun participating in the research. Reasonable foreseeable factors that may be expected to influence the participants' willingness to participate such as sensitive topics, privacy issues, and embarrassing situations were be explained as well. According to Shaughnessy and Zechmeister, (2006), a researcher has the ethical responsibility to make clear to the participant what the research entails, including any possible risk to the participant, and to respect the dignity and the rights of the individual during the research experience. I explained to the participants the manner in which their identity will be kept confidential. Permission to record the interview was obtained from the participants.

The interviews were face to face open ended questions, which took approximately 45 minutes to one hour each. The participants were asked to respond to the open-ended questions. I followed up incomplete or ambiguous answers to open-ended questions in order to obtain additional information from the participants. According to Patton (2002), conversational interview provides a great deal of flexibility that helps the researcher to pursue information depending on the information that emerges from talking with the individuals in the setting.

The interviews were audio recorded with the permission of the participants. Field notes were collected after the interview throughout the study. The notes included the description of the information obtained from the interviews, and thoughts obtained from transcribing the data. The field notes and the transcripts were examined for prominent categories of information based on the text. Interviews continued until new information obtained from the interview did not provide themes, insights or perspectives into the categories. This was done by doing line by line coding developing categories that emerge along with their relationship. The participants were informed about follow up interview to confirm the audio transcript for credibility.

## **Data Analysis**

Data management is important for qualitative researchers. According to Miles and Huberman (1994), qualitative researchers have the responsibility for keeping track of data because of the large amounts of data that come from several cases or sites. The data analysis begun concurrently with notes taking during the interviews. Once the interviews were transcribed, I reviewed for accuracy and analyze. I then begun to look for themes that are related to the research questions. The information obtained from the participants were broken down into similar thoughts and themes a process Creswell (2007) refers as coding. Coding will allow this researcher to identify similarities in thoughts among the participants (Creswell, 2007). As I read the data for clarity, I also searched for potential new topics, organized the topics into columns, and looked for similarities to merge them together.

More detailed analysis begun with coding the data by organizing the data into similar statements, phrases, terms or sentences. Each individual theme was labeled with a coding for later identifications. I then clustered the significant meaning concerning the shared experiences and perspectives of the study participants into themes. The meaning was developed from the recorded interview session and field notes. The themes were placed in a spread sheet. This allowed this researcher to use textural and structural description of the participants' experiences, beliefs and perceptions. The themes were then synthesized into a combined description of overall essence concerning the participants' experiences (Miles & Huberman, 1994). I used some specific phrases directly from the interview. According to Creswell (2009), quoting research participants phrases shapes the themes into general description.

# **Issues of Trustworthiness**

I utilized member checking for credibility. Member checking is a technique qualitative researchers use to improve the validity, accuracy, and credibility of a study (Patton, 2002). Member checking provides the participants with opportunity to validate their statements and to correct any statement that might be misinterpreted. Member checking technique involves providing the participants with interview transcripts for content review (Creswell, 2007). Creswell (2007) recommended sharing data, analysis, interpretation, and conclusions with research participants in order for the participants to assess the credibility and accuracy of the researcher's account. I provided the participants with instructions for reviewing the transcripts to ensure that the participants fully understand the process. I performed member checking during the initial interview, follow up interview, and upon completion of data analysis. Shaufhnessy and Zechmeister (2006) recommended sharing only pertinent portions of the interview transcript to the participants as too much information could be overwhelming. I provided three of the participants with pertinent portion of the transcripts for review during the second interviews and received feedback. For the other three, I contacted them on the phone contact, provided them with the information and asked for their feedbacks. According to Patton (2012), a researcher can gain knowledge on the accuracy, completeness, fairness, and the perceived validity of data analysis if the participants provide feedback on the description and conclusion of the study.

The credibility of qualitative research depends on rigorous methods, the credibility of the researcher, and the philosophical belief in the value of qualitative research (Patton, 2002). To ensure transparency and trustworthiness of the current research, I incorporated an audit trail into the research design (Bowen, 2009). Bowen (2009) noted that audit trails involve the researcher documenting the methodological steps taken to arrive at their findings, interpretation, and conclusion. The interviews were transcribed verbatim using thick description. Themes were created based on the data that were obtained from the participants. I searched for alternative themes and different patterns until I could not find strong supporting evidence for alternative ways for presenting data. Searching for alternative themes will increases the confidence in the original explanation that I will generate as recommended by Patton (2002). The audit trail helped this researcher to ensure that patterns, themes and concepts are grounded in the data (Bowen, 2009). The final section contain discussion of the relationship of the finding

to other existing data and the findings implication for future research. The limitation of the study was reported as well.

# **Ethical Consideration**

Informed consent is an essential component of the social contract between the researcher and the participant; therefore, informed consent was utilized in this study (Creswell, 2009). At the beginning of the interview, I asked the participants to identify themselves as 18 years or older in order to inquire whether the participants have the capacity to consent. I explained the scope and nature of the study to the prospective participants. The participants were informed and shown the IRB approval for this research. The participants were provided with information concerning participation in the activity that reasonably might affect their willingness to participate including limits of confidentiality and monetary or other cost of reimbursements.

The voluntary nature of participation was explained to the participants. The participants were informed of their rights to refuse to participate in the study and to withdraw from the study. I ensured that the participants have freely and without undue influence expressed consent and have had the opportunity to ask questions and receive answers regarding the activities. The manner in which information about participants will be kept confidential was explained to the participants in order for them to judge for themselves whether the safeguards taken to ensure their confidentiality are reasonable.

In order to protect research participants from social injury, I asked the participants not to use identifying information and the participants' response were made anonymous through pseudonyms in the published report. The participants were assigned code numbers. I linked the participants' names with the code number on a master list and access to this list is restricted by keeping it under lock safe.

I complied with ethical guidelines set forth by Walden University's Institutional Review Board (IRB). According to Shaughnessy and Zechmeister (2006), colleges and Universities are mandated to establish IRB by National Research Act of 1974 in order to ensure that researchers protect participants from harm and safeguard participants' rights. All research materials and raw data are secured in a safe lock-box in my house. The information will be secured for a minimum of five years as recommended by IRB. Computer data will be deleted. Audio recordings will be destroyed by professional data disposal Company.

#### Summary

This qualitative study utilized hermeneutic phenomenological approach to examine the personal experiences, attitudes and perspectives of a sample of African American adults with chronic health issues and diabetes complication. I recruited, selected, and interviewed a purposive sample of six participants from Hudson Valley region in New York. The similarities of the participants included being an African American adult at least 18 years of age with diabetes, having diabetes complications, and having had some type of health insurance at the time of diabetes diagnosis to present. Informed consent was put in place in order to protect the research participants from social injuries and to maintain confidentiality of information obtained from the participants.

The study was guided by research question; What is it like for African Americans adults with chronic illnesses associated with diabetes navigating factors that contribute to racial ethnic health disparities? All raw data were managed and coded using qualitative data analysis. To ensure that trustworthiness and rigor of the study, member checking will be incorporated into the data analysis process. Chapter 4 will present an in-depth analysis of data collected during the research.

#### Chapter 4: Results

In this study, I employed a qualitative research design in the examination of six African American adults with diabetes complications with the aim of expanding the understanding of the phenomena of racial ethnic health disparities. I adopted an interpretative phenomenological analysis using in-depth interviews. The overarching research question guiding the study was the following: What is it like for African Americans adults with chronic illnesses associated with diabetes navigating factors that contribute to racial ethnic health disparities?

The purpose of Chapter 4 is to report the study finding from the interview of the six African American adults with diabetes complications and have health insurance prior to diagnosis to present. This chapter is organized in various sections, beginning with a detailed explanation of the sample size, screening and methodology for recruiting participants, demographics of each participants, interview procedure, and data collection. An in-depth explanation of how data were interpreted and themes that emerged from the data will be presented in this chapter. In this section, I explain how I maintained the integrity of this qualitative study through credibility, transferability, dependability, and confirmability. The results section provides study research findings including detailed information from the transcripts, which will be the participants' stories.

#### Sample Size

The sample size for this research was based on a review of existing qualitative research. According to Miles and Huberman (2005), qualitative researchers typically work with small sample size of people that fit in their context and studied in depth. The

sample size for this study was a minimum of six and a maximum of eight. Miles and Huberman (2005) noted that qualitative studies are conceptual-driven resulting in sequential sampling instead of specific sample size at the beginning of research. Getting the number of sample size was challenging. The study proposal was approved at the beginning of winter months in New York. Several potential participants did contact me, but chose to wait 3 to 4 months later to be interviewed due to the winter weather.

The final study sample was six participants, which was based on the information received from the six participants. Qualitative researchers focus on in-depth information rather than generalizations, and thus small sample size. Mason (2010) stated that the sample size for qualitative data should be large enough to ensure that most of or all important information, concepts, and perceptions are uncovered in the data, but too much data should be avoided as perceptions will be repetitive and eventually redundant. The data were not producing more information after interviewing the fifth participant, which led me to believe that I had reached a point of diminished return as documented by Mason (2010). The sixth participant did not offer any new insight on the categories created from the data. Furthermore, I was concerned with the experiences of the participants and not generalization. Therefore, no further collection of data was necessary once the saturation stage had been reached, as noted by Patton (2002).

In addition to reaching saturation, the recruitment of participants in this study was difficult, which made the research take longer than it was expected. Flyers were placed in doctors' offices and public places that are frequented by African Americans, churches, barbershops, and hair and nail salons. The pastors for the three churches I approached to

announce the study or disseminate the flyers denied me the opportunity, but asked for me to post on the church announcement wall in the lunch rooms. Some of the potential participants who contacted me turned down the study due to wanting monetary reimbursement. Each participant was reimbursed for travel cost at \$20. A number of participants did not show up for the scheduled interviews and did not return my calls.

### **Sampling Method**

I employed purpose sampling and snowball sampling to recruit participants in this study. I posted a flyer on Facebook and endocrinology offices in Hudsona Valley Regions in New York. I also posted and distributed flyers in various public places that are frequented by African American adults (e.g., churches, barbershops, nail salons, hair salons, grocery stores, and libraries). All of the six participants reported having heard about the study through a friend or relative who received the flyer from the locations that I distributed the flyers, specifically to two hair salons and a barbershop. Appendix A is the sample of the distributed flyer.

## **Screening Process**

The potential participants contacted my cell phone number, which was noted on the flyer. I created a phone log to document phone conversations. Callers had to meet the eligibility criteria: (a) African American adult at least 18 years of age, (b) must have diabetes with complications, (c) must have had some type of health insurance at the time of diabetes diagnosis to present, and (d) must live in Hudson Valley Region in New York State. The callers were screened using the above criteria questionnaire (Appendix B). The screening and recruitment were done over an 8-month period. Several callers either did not meet the criteria or were not willing to participate in a face-to-face interview due to the winter weather. One of the participants was snowballed into the study by a mutual friend and one by a coworker. The rest of the participants were snowballed by those who saw the flyers in various public places. An interview appointment was scheduled if the caller met the criteria. I called the participants to confirm the interview appointment on the scheduled interview date.

## Settings

Interview sites were selected by the participants themselves for their convenience. For safety reasons, interviews were conducted in public places, which were Park, Mall food court, KFC restaurant, and Dunkin Donut café, which were near the participants' residence. All the participants drove to the interview site. After greeting and introducing each other, each participant was provided with consent form (Appendix C). The participants were asked to read the consent and ask questions. The participants were reminded of the voluntary nature of the study and that the information they provided during the interview would be kept confidential. The participants were also informed that pseudonyms were to be used on the research documents. After reading the consents, the participants signed copies of the study consent. A picture of the signed consent was sent to each participant through text message and/or during interview follow-up meeting.

The participants were asked to respond to 10 open-ended interview questions. By interviewing the participants directly, qualitative researchers get to understand the experiences from the perspectives of the individuals who live those experiences (Rudestam & Newton, 2007). Through face-to-face interviews, the participants were able

to obtain clarification when questions were unclear, and I was able to follow up with incomplete or ambiguous answers to the open-ended questions, as noted by Shaughnessy and Zechmeister (2006). At the conclusion of the interview, a follow-up interview was scheduled in a few weeks after the initial interview. The purpose of the follow-up interview was to allow the participants to review the interview transcript and clarify any information that warranted clarification. Only three of the participants attended the follow-up interview. The other three participants preferred for the follow-up interview to be performed via telephone.

# **Demographics**

Six samples of African American adults residing in Hudson Valley region in New York participated in face-to-face interviews. Pseudonyms for the participants are Mary, Brenda, Pamela, Eileen, Esther, and John. The age of the participants ranged from 46 to 62. The demographic of the participants were obtained during initial screening telephone call. All of the six participants met the criteria of African American adult of 18 years or older, having health insurance at the time of the initial diabetes diagnosis to present, having health complications of diabetes, and living in Hudson Valley Region in New York State. The participants needed to be experiencing at least one of the following diabetes complications: high blood pressure (BP), heart disease (HD), kidney disease (KD), stroke (ST), vision impairment (VI), hearing impairment (HI), vascular disease (VD), nervous system disease (ND that cause carpel tunnel syndrome and slow digestion of food in stomach), or periodontal disease (PD). All of the participants had multiple diabetes complications as reflected on Table 1. All of the participants reported having BP, two participant reported VI, four participants reported having VD, five participants had ND, four participants reported having HD, three participants had KD, and two had PD. Table 1 contains the data from qualifying diabetes complication questionnaire for the 6 study participants.

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Demographic	Mary	Brenda	Pamela	Eileen	Esther	John
Gender	F	F	F	F	F	Μ
Age	46	62	60	62	55	60
BP	Х	Х	Х	Х	Х	Х
VI				Х		
VD	Х	Х			Х	Х
ND	Х	Х			Х	Х
HD	Х			Х	Х	Х
KD		Х	Х			Х
PD		Х	Х			

Participants' Demographic characteristics of the study

The study was open to African American adults. All of the participants had health insurance.

# **Data Collection**

Data were collected using in-depth, semistructured, face-to-face interview protocol. The interview protocol consisted of a set of questions to induce the six participants' recollection of how they felt when they received diabetes diagnosis, their experiences with diabetes, SES factors that influenced their health care, and other key factors centered around the research questions and theoretical framework. The participants were encouraged to share their stories. I asked the participants to clarify vague answers and probe for more information whenever it was necessary. I did more probing with Eileen and Pamela who seemed to have been not open for deeper reflection.

The date were collected in Tuxedo Park, Dunkin Donut in Nanuet, Palisades Center Mall in Rockland County, KFC in Middletown, and a park in Poughkeepsie, all located in Hudson Valley region in New York State. The initial interviews took 45 minutes to 1 hour, Follow-up interviews lasted about 15 minutes to 20 minutes. Data collections lasted about 7 months. Obtaining participants for this study was challenging as most of the potential participants wanted monetary reward and no responses from the potential participants. There were no responses from potential participants despite the dissemination of the study flyers in places that are frequented by African Americans and in endocrinology offices.

The initial interviews were audio recorded. During the interviews, I took minimal notes in order to focus on each participant's account of his or her stories. Following each interview, I completed a reflection of the interview encounter and the impression of each participant. The transcripts were analyzed post each interview and transcribed into a note book. Each participant reported that the transcript summary presented accurate interpretation of his or her interviews. Also, reflexive notes were created during screening and interview process. The screening questionnaire, consent forms, audio tape, and memoranda were set up for each participant and were kept in a locked safe in my home.

# **Participants**

Six African American adults from Hudson Valley region in New York State agreed to participate in this study. Each of the six participants provided compelling stories and perspectives that were individually unique. However, all of the participants had similar experiences with coping with diabetes diagnosis, ecological barriers, behavioral challenges, socioeconomic barriers, managing diabetes, and racial discrimination. Each participant told his or her stories of how he or she received diabetes diagnosis. To maintain confidentiality, the participants' real names were replaced with pseudonyms.

# Mary

Mary was a single mother of two children. The oldest child had his own family while her last child was in college. Prior to having her first child, Mary did not have well visits. She reported that she enjoyed going to her doctor's office for prenatal medical checkup and post-delivery when she took her baby for routine checkups. Those visits motivated her to have her own well visits to her primary physician. She attended annual well visits for 2 years post-delivery of her first child. Mary reported that the cost of copays and a lack of time prevented her from having regular well visits; however, she resumed the visits when she got pregnant with her second child.

Mary reported that she did not get a diagnosis of diabetes until after having her second child in her mid-20s. According to Mary, she had a healthy pregnancy, but gained a great deal of weight. She was admitted at the hospital for an extended period of time postdelivery due to high BP and having had cesarean section. Mary believed that she developed high BP and diabetes as a result of long stay at the hospital. Mary claimed that she had a fear of staying in the hospital and this was her first admission into the hospital. Mary felt that the fear of hospitalization triggered high BP and the high BP triggered diabetes. However, she did not receive a diagnosis of diabetes during this hospitalization. Upon discharge from the hospital, Mary was advised to seek nutritional consultation based on her weight gain.

Mary joined a program for losing weight in New York City post-hospitalization. At the program, the participants were mandated to have their BP and blood sugar checked after dietary class, which was before exercising class. During her first visit, Mary's blood sugar was high. The nurse who checked Mary's blood sugar referred her to see an endocrinologist associated with the program. Mary reported that the endocrinologist diagnosed her with diabetes after a series of medical tests. Mary did not believe she had diabetes because no one from her family had been diagnosed with diabetes or any other chronic health issue. She did not know anyone with diabetes. She reported having believed that the doctor just wanted to make money. The endocrinologist who provided her with the diagnosis informed her that she was at an early stage of diabetes that could be reversed. Mary did not go back to the program and did not follow up with any physician until she got sick. She went to emergency room and was admitted into the hospital. After a series of medical tests, Mary received a confirmation that she indeed had diabetes. She was issued prescriptions of oral diabetes and BP medications at the time of discharge. Mary did not follow this treatment regimen right away because she did not believe she had diabetes.

Mary continued to struggle with managing diabetes with the same treatment regimen and reported having physical pains. Her diabetes complications included high BP, VD, HD, and ND. She reported that she lived alone, which has encouraged unhealthy eating habits. Her son was married and lived with his family out of town while her daughter was away in college. Her children, her brother, and her sister have always been her support network that encourages her to eat healthy. Mary stated that she was always able to maintain a good blood sugar levels when she cooked at home for her children. Mary stated that she does not cook at home anymore. She purchases every meal at either a Haitian restaurant near her or fast food restaurant because she has no one to cook for. Mary does not check her blood sugar two times daily as recommended by her physician. She reported fearing to check her blood sugar and had not had someone to check her blood sugar for over 2 weeks at the time of the interview. Her sister, who was a medical doctor, usually stops by to check her blood sugar levels, but had been out of town for a conference.

According to Mary, her job was stressful and raised her blood sugar. She stated that her BP and blood glucose levels are always stable and within normal limit when she is off work for some time. At the time of the interview, Mary had been on family medical leave for 2 months. Mary reported that her blood sugar and blood pressure were great at her doctor's office 3 weeks prior to this interview. She did little to no physical activities. I stopped reviewing here due to time constraints. Please go through the rest of your chapter and look for the patterns I pointed out to you. I will now look at your Chapter 5.

# Brenda

Brenda was one participant who was very eager to be interviewed to tell her story. She heard about the study from her friend, who picked up the flyer from a hair salon. Brenda travelled 45 minutes to my town for the interview. During the initial telephone screening, Brenda stated that she had been looking forward to the day she could be interviewed about her experiences with diabetes. She also wanted to come to the town in order to go to a Casino near the town. Brenda stated that she chose to be interviewed at a fast food restaurant in order to eat fried chicken without feeling guilty because she wanted to stop unhealthy eating habit after the interview. Brenda is a 58 years old single lady who has never been married, but once lived with her boyfriend. She received the diagnosis of diabetes in her mid-thirties.

Brenda reported that she thought she was a healthy individual than majority of people until she received diabetes diagnosis. Brenda posited that stress negatively influences individuals' health and having families is very stressful. However, she was stressed at one point in her life when her ex-boyfriend messed up her credit through gambling. With this notion in mind, Brenda felt that as a single woman, never been married and had no children, there was no need to have a well visit. She visited health care provider's office only when she was sick, which was rare according to her. Brenda never had any well visit to health care providers until the organization she worked for introduced a wellness program. She worked for a non-profit human services organization that provided services for individuals with developmental disabilities. The program required that the organization nurses checked employees' blood sugar and blood pressure quarterly. The wellness program also required the employees to complete annual physical medical examination at a health care provider's office. The employees in return received \$300 bonus pay post the annual medical examination. Brenda did not take full advantage of the Wellness Program right away. Instead, she participated only on the mandate quarterly program, which was conducted by the organization nurses.

Brenda reported that her blood sugar was 90 when a nurse checked her blood sugar some time in 2012. The nurse advised Brenda to see a medical doctor, but Brenda ignored. In 2013, Brenda started feeling sick and decided to complete her first annual medical examination for wellness program compensation. During that visit, Brenda received a diagnosis of diabetes and was placed on Metformin and insulin. She continues to receive the same treatment regimen. She struggles with following doctor's orders specifically the diet orders. Brenda reported being a heavy smoker and struggling with ways to stop smoking. She suffers from vascular disease, nervous system disease, high blood pressure, periodontal disease and kidney disease. The vascular disease was evident with her swollen legs and hands. She like to go dancing in the bars that has assisted her with maintain her ideal body weight. However, she drinks heavily while out in Bars.

# Pamela

Pamela was snow balled into the study by Brenda. She is a 60 years old African American woman with a family of three children and several grandchildren. Pamela reported that prior to receiving diabetes diagnosis, she had other medical problems that required her to complete blood work every 6 months at her gynecologist's office. As per Pamela, she did not have well visits until after she developed some medical problems. During one of the visits to her gynecologist, Pamela's blood triglyceride was high. Her gynecologist referred her to see primary physician.

Pamela was hesitant to see a primary doctor, of whom she didn't have. About two weeks post seeing her gynecologist, Pamela started experiencing tingling of her hands, frequent thirst for fluid, frequent urination, feeling dizzy and sad most of the times. One day while getting off bed during afternoon nap, Pamela fainted on the floor. She was not sure how long she was on the floor, but became alert when her husband opened the bedroom door. She took a glass of orange juice and felt better. Pamela and her husband checked the phone book and got a phone number for a primary physician. Pamela was seen by the primary physician the following day. At the doctor's office, her blood pressure was high while her blood sugar was low. The doctor performed a series of tests including drawing blood. Pamela was provided a sample of medications and recommendation of one week follow up with the doctor. She received diabetes diagnosis at the primary physician's office during the follow up appointment. She was prescribed for oral medication and insulin right away and has since been on the medication. Pamela reported having felt destroyed because she always heard that diabetes is a bad disease and had no knowledge of what the disease was about and that there were books and other materials that she could read. However, her physician was provided her with a great deal of information that was very helpful to her.

According to Pamela, her major struggle with diabetes was a result of late night snack and smoking. She liked to eat ice cream prior to going to bed. Pamela reported having read books on diabetes that really helped her maintain healthy eating habits and
changed her lifestyle during the early months of her diagnosis of diabetes. She begun to go for walks every morning after work. She worked overnight shifts and stayed home with her children in the day. Although Pamela stopped eating heavy meal late at night, she continued to eat ice cream late at night and did not stop smoking. When her blood sugar did not stabilize, Pamela stopped having ice cream and other late night snacks. With the change of her life style, Pamela's blood sugar levels stabilized and all her medications dosages were lowered. However, Pamela continued to self-check her blood sugar levels two times a month.

Seeing that her blood sugar was stable, Pamela resumed her old life style and stopped going to her regular three months follow up with her physician. About six months after not paying attention to her lifestyle, Pamela began experiencing some diabetes symptoms, but ignored them. One day driving from work, Pamela got dizzy and got into a motor vehicle accident. She was taken to medical emergency room (ER) by ambulance. Her blood sugar was very low at ER. Pamela was admitted into the hospital for two weeks. After a series of tests, she was informed that she had diabetes complications of high blood pressure, and kidney disease. In addition to these diagnoses, Pamela currently suffers from periodontal disease. She is back to taking oral diabetes medications and insulin. Pamela reported that she does not see endocrinologist because of high co-pay medical fee. Instead, her primary physician is treating her diabetes. Pamela has diabetes complications of high blood pressure, nervous disease, kidney disease, periodontal disease. She reported having physical pain associated with the complications.

## Eileen

Eileen was a single mother and a grandmother. She divorced when her daughter was 10 years old. Eileen reported that her ex-husband was addicted to gambling and used up her credit cards. Her husband left her with huge debt; therefore, Eileen had to work two full time jobs in order to pay off the debts, take care of her daughter and her mother, and save for her daughter's college funds. She fell one day at one of her jobs. She was taken to emergency room (ER) via ambulance. At the ER, the doctor ran tests and checked her blood sugar. Eileen received a diagnosis of diabetes with blood sugar level of 500. She was hospitalized for 7 days. She resigned from one full time job upon discharged from the hospital.

Prior to diabetes diagnosis, Eileen used to have annual medical examination at her primary doctor's office. She reported having been informed in the past during an annual medical appointment that she was at pre-diabetic stage due to elevated blood sugar and blood pressure. The physician did not provide her with any recommendation despite telling her that her blood sugar level was elevated. She dismissed the idea of ever getting diabetes because the doctor did not warn her. At that time, she did not know that her mother died of diabetes when she was 5 years old. As per Eileen, she used to experience symptoms of diabetes such as feeling thirsty all the time and tingling of her feet and fingers. However, she did not pay attention nor visited a health care provider.

According to Eileen, she took the diagnosis serious post hospitalization. Eileen asked the doctor what she could do when she got home. The doctor provided Eileen with diabetes plan of exercising and changing her lifestyle, watching what she ate, and not to eat carbohydrates. She started walking every morning, reduced the number of cigarettes she had daily, and eliminated carbohydrates and sugar from her diet. Eileen took Diabetes course at Nyack hospital in New York. She reported that the class was informative to her, showed her how to self-check her blood sugar levels, chart her blood sugar levels and bring the sheet to her doctor, and offered blood test for AIC at the laboratory every three months.

Although she worked so hard to maintain healthy lifestyle, Eileen could not eliminate smoking, sweet ice tea, sneakers bars, and bread. However, her blood sugar levels and blood pressure was stabilized with the lifestyle changes. She followed other physician orders by checking her blood sugars three times daily, took her oral medications, and kept her monthly medical appointment with her endocrinologist. She was doing well until her endocrinologist stopped accepting her health insurance. There was only one endocrinologist in the County she resided in. She decided to make out of pocket payment and reduced her visits once a month to once every three months. Eileen reported being discouraged due the attitude the doctor and the receptionist showed her during the appointments. She stated that she think that she was treated differently because she was late with her payments.

Eileen took on a second job again to help pay for her medical expenses. She stopped exercising because of lack of time. The stress at the two jobs led to unhealthy lifestyle such as eating foods that she had eliminated and heavy smoking. She also put off seeing the doctor until she could pay off the medical bills. When all the diabetes symptoms reappeared, Eileen started checking her blood sugar daily. She asked her primary family doctor to help treat her diabetes. During one visits at the primary doctor's office, Eileen complained of pain on her eyes and chest pain. She received additional diagnosis of heart disease after a series of tests at her primary physician's office. The doctor referred her to the ophthalmologist for the issues with her eyes. She is receiving injections on both eyes monthly to prevent her from getting blind. Eileen reported feeling frustrated after the injections because she cannot drive and has to be in doors for at least 48hrs.

Eileen retired in 2014. She has since gotten a new endocrinology who she stated has helped her a great deal with controlling diabetes symptoms. She stated that she does not experience stress anymore because she does not have to go to work and deal with coworkers and supervisors. She has time to go to for walks. She volunteers two times a week to serve lunches at local schools. She stopped smoking and feels good about herself. Her current health insurance cover a great deal of her treatment. She hope one day her insulin injections will be discontinued. She currently experience diabetes complications of high blood pressure, vision impairment, and heart disease.

## Esther

Esther was a 55 years' old married woman with 7 children. She reported not having any well visits to a physician except during her pregnancies. Although Esther felt sick on several occasions prior to diabetes diagnosis, she did not seek medical care at a healthcare provider's office. Instead, she treated all her illnesses through over the counter medications. She reported not having time to seek medical attention because of having worked one full time job, and one part time job. She had healthy pregnancies and healthy children. No one in her family had chronic health issue.

Esther struggled to maintain healthy weight from when she had her first child in 1980 to present. She experienced symptoms of diabetes such as frequent urination, excessive thirst for fluid, heavy/swollen hands, and tingling of her feet, but ignored the symptoms. Esther thought frequent urination was due to drinking plenty of water, but could not explain the source of swollen hands and tingling of her feet. She stated that she could not take time off from work to seek medical attention because her husband was home on disability. Esther did find out she had diabetes when she fainted in church and was rushed to the hospital. She was hospitalized for little over one week. She was started on insulin and oral medications.

The diagnosis of diabetes devastated Esther. She lost hope in life and felt that she was going to die before her last child graduated from high school. The child was in high school at the time Esther received diabetes diagnosis. The doctor at the hospital informed her that she had diabetes complications that would be difficult to reverse. The doctor referred her to see endocrinologist in two days after discharge, to provide her to provide her with treatment plan. She was instructed at the hospital to stop eating certain foods, which made her feel as if the doctor was blaming her for destroying her life. Esther stated that she did not even eat half the food the doctor instructed her to stop eating right away. The doctor recommended not eating fried chicken, French fries, and pasta. Esther was depressed for months not having known any.one who survived the disease. She started to

eat even the foods that she was warned not to eat. Her husband and children encouraged her and informed her that she could survive this, but she ignored them.

One day at work, Esther opened up to her coworkers and informed them of her struggle with diabetes. She was surprised to find out that her supervisor had lived with diabetes for over ten years. Esther gained courage and started look in the internet for documents on diabetes. She was happy to read stories of individuals who had lived successfully with diabetes; however, other individuals' stories scared and discouraged her. Her son printed out for her stories of individuals who had lived successfully with diabetes, which was helpful to her. This prompted her to see the endocrinologist as it was recommended by hospitalist.

Esther reported having felt better after the endocrinologist visit. The endocrinologist referred her to a nutritionist, and recommended diabetes educational classes, exercise, for her to cut down on carbohydrates, salty foods, and sweetened foods. When she got home in positive attitude, her husband cleared the food pantry and refrigerator of any food that was not good for her health. Her husband and children did grocery shopping for a few months and made sure that they purchase healthy food. Her husband drove out of their town to purchase fresh vegetables from a farmers market. When Esther started feeling well, had great deal of energy with good blood sugar levels, she asked her family to let her do tasks she used to do prior to diagnosis. On her first trip to the grocery store, in addition to purchasing vegetables and fruits, Esther reported having purchased foods that she couldn't eat based on the doctor's orders. She wanted her family to enjoy eating what they used to have prior to her diabetes diagnosis. Esther ended up eating the food that she cooked for her family. Esther stated that she felt comfortable eating foods that the doctor had asked her not to eat because she was using insulin and walking daily in the evenings with her husband. For a long time, Esther felt better despite eating carbohydrates, salty foods, and fried foods. However, everything changed when her husband went back to work.

Esther could not take evening walks without her husband. She did not want to drive alone twenty minutes to go to the park for a walk. She had nowhere to walk in the neighborhood she resided in during the early years of her diagnosis. Esther has complications of high blood pressure, vascular disease, and nervous disease.

## John

John was a 60 years old man who has lived with diabetes for about 30 years. He is a married father of three adult children. John suffers from numerous diabetes complications. John reported that prior to receiving diabetes diagnosis, he had been to a health care provider's office only for annual check-ups when he was in college. This was a mandate from his college. He stated that he was healthy back then and never received negative feedback from health care providers. John reported having gained a great deal of weight after college and blamed it on his job. At his job, John sits on a desk in front of a computer all day.

John experienced some diabetes symptoms for a long period of time, but failed to seek medical attention. He could complain about body pains and feeling dizzy to his wife and work colleagues. All the individuals he informed about his symptoms encouraged him to see a medical physician, but he failed to do so. While having pizza for lunch at work one day, one of his colleagues made a joke to him that he would die of diabetes. John stated that this bothered him knowing that he did not have diabetes. When he informed his wife about the colleague's statement, his wife informed him that he needed to be checked up. John made a doctor's appointment for the first time in his life. During the initial doctor's appointment, John was shocked when the doctor asked him if he had diabetes. The question was based on his Hb A1c report. He did not realize the doctor had checking for his Hb A1c when labs were drawn. The doctor assumed John had diabetes. He was placed on diabetes, high blood pressure, heart disease, and asthma medications.

John reported being torn apart and being depressed for a long period of time. He thought he was going to die as his work colleague had stated prior to him receiving the diagnosis. The doctor did not provide him with detailed treatment regimen except for the oral medications. Prior to the diagnosis, John led sedentary life style and did not practice healthy eating. John reported having been depressed and taking one week off from work immediately after he received diabetes diagnosis. During that week, John ate unhealthy food, smoked and drunk a lot of alcohol. He did not know anyone who had diabetes and did not know how to get information on care. When John returned to work, he was met with a great deal of support from his colleagues. The Coworker who had made jokes about John possibly dying of diabetes confessed to him that he had diabetes. This coworker and other peers educated him on diabetes management and walked with him during lunch breaks.

John reported having difficulties changing his dietary habits although he received support from his wife and other family members. His wife started cooking healthy and purchasing a lot of fruits and vegetables. However, John continued to eat unhealthy while at work. He would tell his colleagues that he was going for a walk but would stop at a fast food restaurant and eat a meal. He also struggled with stopping smoking, but was unsuccessful. He developed further complications very fast and was hospitalized on numerous occasions. He cancelled our interview once due to being hospitalized. During the interview, John reported that he had scheduled surgery to amputate his legs. At the follow up meeting, John's legs had been amputated and he was in a rehabilitation center. John experiences complication of high blood pressure, vision, vascular disease, nervous disease, heart disease, and kidney disease.

#### **Data Analysis**

The data was transcribed into notes in a note book. I listened to the audio recording and transcribed the data into note book. The transcript had time stamp for easy access. After transcribing each participant's data into a note book, I listened to the audio recording while reading the notes to verify the accuracy of each transcript, and correct any mistake. I re-read the transcript several times and took notes as I captured my thoughts about the participants.

The data was hand coded through open-coding and a table was prepared with two columns. The first column was for inductive categories and the second column was participants' responses. I first looked for words that were commonly used and highlighted the words. I looked at the themes that were predominant then categorized the themes into larger thematic groups as recommended by Gibbs and Taylor (2005). A new code was created whenever a theme was identified from that data that did not fit the existing codes

as noted by Gibbs and Taylor (2005). I had to read through the data several times and the more I read the data, the more the themes became apparent. Open coding continued until the categories were saturated. Finally, I completed selective coding whereby the categories were integrated and redefined to present a theoretical model.

# Overview of Research Findings

Seven salient themes emerged from the personal experiences of a sample of African American adults with diabetes complications. The seven emergent themes elucidated various aspects of Racial Ethnic health disparities. The data is grounded through use of participants' quotes in each thematic description. In other words, the women were empowered to name and describe their personal experiences living with diabetes.

#### **Theme 1: Beliefs and Perception of illness**

Each of the participants gave an account of how they felt and perceived diabetes diagnosis from when they received the diagnosis to present. Consistence with health belief model, the participants' attitudes and health behaviors depended on how they perceived the illness at that time.

When **Brenda** received the diagnosis of diabetes, she perceived the disease as something that if not under control, could kill an individual. She took the doctor's recommendations serious and changed her lifestyle:

I felt horrible when the doctor told me I had diabetes because you hear these stories of diabetes silence killer. So many negative things about diabetes. Every time I went shopping, I had to empty my cabinets. All the junk foods had to go. I think I got depressed. I started following what the doctor told me to do. I had to bring in my nephew to live with me. This helped me cook at home, healthy eating you know. I started to cook healthy foods. I stopped taking sugar. I made attempts to quit smoking. I didn't want to die. I tried E cigarette for about one and half months. I did exercise, racket ball with family support.

A few months later, Brenda's perception of the disease changed. She started hearing stories of people who have survived diabetes by taking prescribed medication only if their blood sugar was either too high or too low. A coworker informed her of an aunt who was living with diabetes for over 20 years, and does not follow all the recommendations except for checking her blood sugar. The aunt would then take her medications if her blood sugar was high. At that point, Brenda thought about the difficulties she was experiencing in terms of the cost of medication and healthy foods, and her negative attitudes towards others. She was angry at people and fought with her sister over very little things:

I thought about my anger towards people. I got angry at people who did not do anything to me. I realized I was not ready to change many things in my life. I wanted to stay the way I was. After all I was dying of diabetes. I never knew anyone who survived diabetes. Everyone who has diabetes dies. After hearing about my coworker's aunt survival skills, I stopped following the doctors recommendations. I went back to smoking. I started drinking. I started going out more to clubs. I don't take my medicine, unless my blood sugar is really high. I mean very high. I don't check my blood sugar daily. My body tells me when my sugar is low or high. When I feel it is high, I check it.

Unlike Brenda at the time of diagnosis, **Esther** acknowledged the illness as a serious disease, she perceived that she was going to die regardless of any effort she put into maintaining a healthy lifestyle. She did not change her lifestyle right away:

When the doctor told me I had diabetes, I felt like I was going to die. I got really depressed and started eating even foods I never used to eat. I was like after all, I have a killer disease. I am going to die. The doctor told me I had full blown diabetes. The doctor at the hospital did not give me any hope. I ate a lot of carbohydrates, bread, pasta, potatoes, chips, sugary foods.

Esther's perception of diabetes changed post reading diabetes articles in the internet and talking openly to people about her struggles with diabetes. She learned that some people live their life to their fullest potential by maintaining healthy diet and exercising. The information she obtained from these sources made her change her lifestyle. Her perception of diabetes as a disease that kills individuals despite changing health lifestyle and following the doctor's recommendations was transformed. In her own words, Esther stated:

I started talking to people about my diabetes. I did some research online, which some were scary and other encouraging. So I decided to focus on reading stories of people who have lived successfully with diabetes. My husband and my children cleared our food pantry and refrigerator. I was eating healthy. They purchased healthy food. I walked daily with my husband. I reduced my sugar intake. I don't sprinkle sugar and molasses on the sweet potatoes anymore. I now take 2 slices of bread a day as opposed to 6 to 8 slices a day. I used to take 2 slices of bread per meal, 3 meals a day. I purchased healthy foods, vegetables, fruits, and fish for myself.

Upon receiving diabetes diagnosis, **Pamela** took the doctor's recommendations serious. She perceived the diabetes as serious disease and if not taken care of, can result into death. She followed the doctor's recommendations with the perception that if she didn't, then she would die:

When the doctor at the hospital told me I had diabetes, I was destroyed...we always heard something that it is a bad disease. But when I got educated, I just realized that it is something that everyone has. I knew a friend who died of diabetes. I did not want diabetes to defeat me, like it did my friend. I followed what not to eat. I just stayed away from what the doctor told me not to eat. I started to eat small portion of everything I wanted to eat. I exercised, walked every day. It wasn't such a big deal. I knew exercise should solve all my problems. I self-monitored my blood sugar. My problem was eating late at night, late snacking. I changed. I ate during the day and went for a walk. I strictly followed the doctor's orders. When you first hear something, you do what the doctor want you to do.

However, when Pamela's blood sugar got stabilized and did not have diabetes symptoms, she went back to her old lifestyle. Pamela's doctor discontinued the insulin and lowered her diabetes oral medications dosages, however; the doctor advised her to continue checking her blood sugar once daily, exercising, and have healthy diet. She then perceived diabetes to be a curable disease and that she could control the disease:

When my doctor had me lowered the metoformin, when he stopped the insulin, I felt good about myself. I knew I was cured. He advised me to check my sugar daily, but opted for two times monthly. I actually went back to my old ways. Late night snacking, ice cream on top of cake. I felt I did not need more extra exercise. The exercise I got from walking at work was enough. After all, I was cured. My hard work paid. Little did I know that I needed to maintain my new lifestyle. I thought that once you don't take the insulin anymore, you are good for the rest of your life. I felt that I could control diabetes. I mean I would develop diabetes issues and not die. Look where I am now. If only.. umm I could have stayed motivated as I was when I was told I had diabetes.

John was devastated when he received diabetes diagnosis. He perceived the disease as serious illness and that he could die. However, he did not know that he could avoid or delay the diabetes related complications if he changed his lifestyle. When asked how he felt when he received the diabetes diagnosis, John stated:

I got depressed. I felt hopeless, embarrassed, ashamed... I was hurt. I knew no one with this disease. All I knew is that fox die of this. No one told me people live. I couldn't go to work, for a week. I ate and smoked like I was going to die the next day. I convinced myself to enjoy life before I die. I promised to eat pizza. I did not want to prolong the suffering a head. John stayed home for one week. Upon returning to work, his coworkers provided the education and support. His wife too made changes to their lifestyle based on information John gained from work. They read diabetes information online. John followed up with his physician after a month and was provided with dietary and physical activities recommendations. John's belief about not being able to survive the disease changed:

My coworkers provided the needed information. Yes my doctor did not tell me what to do. I was broken in his office. The look on his face said it all... that I was going to die. My coworkers started walking with me, at lunch time. They checked to see what I ate. No I didn't bring lunch. I bought lunch. We bought lunch at a deli. I used to get lunch from Chinese place, pizza shops. At home umm, my wife started cooking good food. Lots of vegetables , fish .I ate fruits. My life changed. However, smoking was a problem and is still a problem. I saw the doctor again after about one month. He told me I could fight this. He told me what not to eat, to exercise. Yes I did exercise at home. We walked together.. my wife and daughter. I wanted to live for my girls.

**Eileen** was very well informed by her physician of what the diabetes entails. Her perception of the disease was that if she did not follow the recommendations, then she would die. She reported that the doctor who informed her about her diabetes diagnosis was very pleasant and offered a great deal of information on her treatment plan. The doctor informed her of all the diabetes complications which are consequences for not following the doctor's orders. I am that kind of a person who do not fall apart, when get confronted with bad news. I listened and asked the doctor what to do. When I thought about all the complications; kidney problem would damage my liver, heart attack, gum disease as per what the doctor told me. I want to live. I don't want to lose a foot, leg. I have a family, grandchildren. I did not want my daughter to come and look at me with tubes in my mouth in hospital. I prayed to stay strong and stay in the right path. I see too many people die, that contributed to their death, not trying to help themselves. Look what you are doing to your family. They have to arrange their schedule to visit you in the hospital. When you get home, they have to take care of you, take off from work. I followed what my doctor told me to do religiously and I stayed healthy.

Having the perception that diabetes is a disease that could kill her encouraged Eileen to change her lifestyle and felt good about herself. However, she developed complications due to the cost of medical treatments when her endocrinologist stopped taking her health insurance and had to pay out of pocket. The change in the physician attitude frustrated her and led to her going back to heavy smoking and picking up a second job to pay for the doctor's visits.

Unlike the other participants, **Mary** did not take the treatment plan serious when she first received the diabetes diagnosis. She did not take the diagnosis serious and did not follow the doctor's recommendations unless her sister who is a doctor and her children are around her. Occasionally, she convinces herself that she does not have diabetes until she gets sick. In her own words, Mary stated; Whenever I try to think about it I dismiss it. My doctor told me if I took it serious, diet and exercise I would improve. I am getting used to it. I know when my sugar is down and when up.

Although Mary sometimes does dismiss the disease, she occasionally perceives the disease as serious illness especially when she get sick and get admitted into the hospital. She tends to follow the doctor's recommendations whenever she thinks about the consequences of her lifestyle.

I get challenged though, when I think of having to take insulin. If I have to go to insulin, I will die soon. I am scared of the needles. You know when you are in insulin, you can't play with that. When I think of this, I take my exercise serious and I call my sister to check my blood sugar or go to her house.

### Theme 2: Denial

Some of the participants did not believe they had diabetes when were first warned by health care providers at early stage.

Mary received pre-diabetes diagnosis and was informed by the physician that she could reverse the diagnosis; however, she did not believe she could get such a diagnosis. In her own words, Mary stated that:

I did not believe I could have diabetes, when I was first informed by endocrinology at the nutritional center. I never thought in a million years that I would have diabetes. That pre-diabetes stage, how could that happen? No one in my family has diabetes. I have never been sick. You know, I went there for training on how to lose weight, and they told me that I was at pre-diabetes stage, because my blood sugar was high. I thought the doctor just wanted money.

There were several consequences for not believing that she was at pre-diabetic stage. Mary waited until she got sick and went to the ER. Even after receiving the diagnosis, being placed in oral medication, and experiencing diabetes complication, Mary continued not to take the diabetes diagnosis as a serious illness:

I do not take the diagnosis serious. Whenever I think about it, I dismiss it. No one in my family has diabetes. My sister thinks I am in denial. You know what, I wish I had believed the doctor because I would have reversed this. But I still feel like it is some form of medical condition. You know why, because I can go days or weeks without checking my blood sugar or taking my meds and nothing happens. However, it hits me that I have diabetes when I get really sick.

Like Mary, **Brenda** did not believe she was at early stage of diabetes when she was first informed of possible diagnosis. In her own words, Brenda stated:

I did not believe the nurse at my work wellness program when she informed me that my blood sugar was low, which was a sign of diabetes. I dismissed her knowing that no one from my family has had diabetes. I started to experience the symptoms of diabetes, symptoms like feeling weak, tingling of my hands and feet, but I ignored them. I said to myself, no, it cannot be. I cannot have diabetes.

Although Brenda took her diabetes diagnosis serious when the doctor prescribed for her Metformin at the ER, she started experiencing denial post a few months of taking the medication. Brenda stopped taking the medication after about 2 months because of the cost and side effect of diarrhea:

I stopped taking the Metformin after a few months. It gave me bad diarrhea. Nothing happened. I had no pain. I did not even tell my doctor. To me that was a sign that I had no diabetes. I was relieved that it was some form of illness. That I had been cured after a few months. I felt so good and went back to my old ways. I wish I knew. I wouldn't be here with you today. My symptoms reappeared almost 6 months later. The symptoms were very severe, the doctor gave me insulin. I mean gave me a script for insulin.

**Pamela** was in deep denial throughout the interview. She repeatedly stated that her diabetes is in control despite the visible physical complications she had.

I don't self-check my blood sugar because it is always stable at my doctor's office. Sometimes I think I no longer have diabetes. I think I am cured. Then I start feeling tingling of my hand. I read several books on diabetes. I am not those people they describe in those books. I do exercise all the time. I walk a lot. But when I go to my doctor, he tell me I have diabetes. I guess I do. But mine can be managed just by primary doctor.

#### Theme 3: Attitude towards health behaviors

As previously noted, an individual's behavior and dietary lifestyle influence their diabetes. All the participants reported struggling with adhering to the diets and physical activities recommended by their physicians. In their own words, the participants reported foods that the doctors asked them to avoid, but they continued taking the foods.

Mary stated that her physician recommended for her to take sugar free foods, cut down on carbohydrates, take oral medication, to exercise, and not to have juice. As per Mary, the oral medication was ordered to prevent kidney damage. Mary failed to adhere to these orders on several occasions from when she first received the diagnosis to present. In her own words Mary stated that:

I don't take my medicine consistently. Sometimes I forget, especially when I am at work. Sometimes they give me trouble than help. The other day, the doctor was fighting with me for not taking my medication. Insurance contacted me recently that I have not reordered my medication in 7 months. I don't think I really need the medicine. I hate when they say you have to take your medicine. What about that day when I don't have to? I don't take everything serious. You know White people take everything seriously, they get crazy. We don't depend on medication. They are not good. If I have to go to insulin, I will die. I am scared of needles. Mary's doctor provided her with a prescription to check her blood glucose level.

She reported not being in compliance with this order. She stated:

When I first got diagnosed, I was given an order to check my blood sugar three times every day, before I eat. I did not follow this order. I checked only once daily and sometimes did not check at all. My doctor, I mean the diabetes doctor fought with me and gave up. He then changed it to once daily. I still did not follow this order. Sometimes I got lazy. Other times I got scared of putting the lancets on my finger. That is the thing that look like a needle used to prick the finger for blood. You know, seeing the blood and the pain caused by the lancet. Sometimes I think it is going to make me loose blood. I don't want to be anemic. We then had another fight and the doctor pleaded with me to check at least every other day. I am not going to check my sugar alone. I have my sister check for me when she is available.

Mary struggles with following the diet that was recommended by her endocrinology. This is usually the case when her children, sister and brother are not around her:

It's me. Laziness prevent me from following the orders. It is overwhelming. You have to decide what to eat after checking your sugar. It is too much. I am currently not cooking at home because my daughter is away in college. I now eat out at restaurants. Yesterday, I went to McDonalds for breakfast. I know rice is not good for me, but I eat it anyway. I buy fried plantain in Hatian restaurant close to me. You know for food to be good in a restaurant, they have to cook something that is not good for you. I fail to understand. When you go out to eat or to a party, you see food that are not good for you, but you still order because you see. For example, last night I went to my sister's. She made good chocolate cake. Her husband secretly told me about the chocolate cake. I asked to taste, then asked for more. I knew my sugar went up, so I took my medicine. That is a perfect example when I take my medicine without thinking of checking my blood sugar first. As a matter of fact, I took 2 pills rather than 1. I knew my blood sugar was off the roof. Avoiding bread is very difficult. I eat bread in all meals even snack. I wake up

hungry and there is no food in the fridge so I eat bread. You know I have no one to cook for.

As per Mary, physical activities particularly exercising, is the most challenging recommendation. In her own words:

I have to really push myself to go for a walk. Walking is sometimes difficult when I have to go to work. From my overnight shift, I run home to sleep. I just get to sit in my car and read a book when I get to the park. I don't go to the gym. When I go two to three times, I get tired. I am not going to dress to go to the gym. I just wake up and in my pajamas, walk to the next door fast food restaurants near me.

**Brenda's** doctor recommended for her to stop smoking, see nutritionist, do moderate exercise and eat right to keep her blood glucose level down. Of all the participants interviewed for this study, Brenda had the greatest challenge with changing her lifestyle and health behaviors. Basically it has been a struggle for Benda to follow the doctor's recommendations. In her own words:

I didn't follow all the recommendations. As a matter of fact, I have not been following the doctor's orders. I didn't stop smoking. I tried by reducing the number I took per day and using E-Cigarette. It didn't work. Cigarette is a challenge. You know it help with stress. I smoke one to one half cigarettes packs a day. I can't help it. It helps calm me down. I try E cigarettes for one month, then stress hit in. I go back to the real thing. I mean smoking cigarette. I also started drinking two years ago, when I turned 60. I am trying to enjoy life because this diabetes is going to kill me.

When Brenda first received the diagnosis of diabetes, she paid attention to her diet and followed through with seeing nutritionist. However, after a couple months, Brenda could not help avoiding her favorite foods.

Doing sugar free drinks, I don't. Do bake and broiled no way. I have a problem with fried food. I can't stop eating fried food fish, chicken. You see, I chose Kentucky Fried chicken for this interview. I was here one hour before the interview. I have already had my fried chicken. Living alone doesn't help it. After work, I don't feel like cooking and I just stop at a place and get food. I don't do exercise. However, I like to go dance in a bar once in a while. Isn't that counted as exercise? I get me exercise at work. By walking up and down the steps to others offices. I am getting office exercise at work. That is good for me. I take my medication when I don't feel well. They are too many. I feel like they are treating side effects for each. I mean each medicine has side effects then they prescribe something to control side effects for the medicine you are already taking. I check my feet with a special object and take the medicine if I don't feel my feet. Otherwise I don't take medication as prescribed. I still have medication from previous year. So I don't fill the prescription.

**Pamela** is one participant who reported having tried her best to follow the doctor's orders and taken diabetes educational classes. However, like the other study participants, Pamela has had some experience of not adhering to the doctor's

recommendations. Her physician recommended for her to eat everything in moderation, but not to eat late at night:

My problem is eating late at night, late snacking. I stopped eating late snack for a while when I got told that I had diabetes. You know when you first hear something, you do what the doctor want you to do. But guess what, I did put ice cream on top of cake every day. I eat during the day and went for a walk. I continued to eat but not late at night. This still did interfere with my sugar levels. I though eating late snack was the issue. Guess what, I ended going back to eating late snack. I must admit, I do it, but I get tired. I mean checking blood sugar to know what to eat.

**Eileen** has struggled with following the recommended diet despite taking diabetes classes and working with a nutritionist. Her endocrinologist advised her to watch what she eats, not to eat carbohydrates and foods that have sugar, and to exercise.

Change the sugar, the hardest thing to give up. Sweet tea, sneakers bar too difficult to give up. I love me some sneakers bar for snack. I gave up pasta and other carbs for a while, but bread. When I check my blood sugar and get high levels, I eat just half the bread, the bottom of the bread. No time to go to the gym. I was working 2 jobs. I got exercise from work.

Among all the participants, John has had the most difficulties changing his lifestyle and adhering to medications regimen:

I have to admit, it has been a difficult journey. Between checking the sugar, knowing when to eat and what to eat, which medicine to take depending on the levels, and creating time for exercise, just exhausting. I have not been able to stop eating some food. Pizza, steak, hamburger, fried chicken, brown sugar on my sweet potatoes umm delicious. I try to convince myself to eat in moderation, but once a taste a piece of them fried chicken, I end up eating 4 pieces. I can't help it. My wife yells at me. She doesn't cook them. I do. Staying away from foods that I love has been difficult. My mother get upset. Exercise, I used to. Once in a while, but not anymore. My legs hurt. Going to be amputated. Oh when I used to walk, I drove to the park by my parents. We walked with my wife. My dad walked with me too. But was not as often as I should have. My body sometimes hurt, at times I had no excuse... I did this to me. I made my own self sick. No I didn't take my medicine routinely, but now I do. I had no time to take them. They were too many. My wife reminded me, but I ignored her. The medicine was too many, got me sicker. My blood sugar, that is a story for another day. I didn't check. Was painful still is, but I check now. I used to check on the weeks I had doctor's appointment. I needed to monitor to be sure to look good, at the doctor's office. Yes I went for all follow ups.

Like everyone else, **Esther** was advised by the doctor at the emergency room to stop eating carbohydrates and foods rich in sugar, and to engage in exercise. At first, she got depressed and started eating even non healthy foods she did not eat before diabetes diagnosis.

I got depressed and ate a lot of carbohydrates, bread, pasta, potato chips, and sugary food. My blood sugar was high every time I checked it. I had to use insulin

to bring it down for hypeglycemia. Too much pain monitoring the sugar.

Controlling what to eat per the sugar levels. That was too much for me.

About two weeks post the diabetes diagnosis, Esther followed these recommendations. However, after sometime, it became difficult for her to maintain the doctor's recommendations.

I just get lazy following my diet. I love bread. I don't know if I will ever stop eating bread. Umm beacon, I don't even want to talk about that. When I went back to work, I went back to eating fast food, pizza, hamburgers between 2 jobs. I felt comfortable because I had my insulin with me. I must say that omitting sugar in my coffee is a problem. I still have plenty of sugar in my coffee and tea. I experience challenge too... fired chicken and fish. You know you are not supposed to eat certain food and you eat them anyway. Bread is a problem, but I know to take 2 slices of bread a day. Ice cream is an issue. I need to learn to stop, but how do I stop. I need a will power.

**Esther** did well with exercising during earlier stages of her diabetes diagnosis. She had her husband go for walks with her. However, her husband got busy at work for a period of time, which resulted into Esther getting discouraged.

I stopped going for daily walks. My husband was not available to walk with me anymore. I think I am lazy. I don't have a lot of energy to take walks. You know it is difficult to exercise, if you didn't before a doctor tells you that you have to. I try sometimes. But sometimes I go for a long period of time without walking. I think I am just lazy.

#### **Theme 4: Treatment Cost**

Consistent with research findings presented in chapter 2, all the participants in this research study experienced financial difficulties in regards to the doctor's visits copays, prescribed medication copays, and the cost of glucometer, needles, and blood sugar test strips. Although some of the participants made great attempts to adhere to doctor's recommendations, the cost of treating diabetes prevented them staying healthy despite having health insurance. **Mary** did well by attending a program for weight loss:

When I got out of the hospital I attended a program in New York City for weight loss. They taught you about nutrition, what to eat and what not to eat. They gave us food to bring home, enough for two weeks. They checked blood pressure and blood sugar. There were machines for exercising. I did not stick to the program, \$75 every other week was too expensive.

Mary's physician prescribed for her oral medications and recommended for her to check her blood sugar at least 3 times daily prior to a meal. However, she does not adhere to these orders. When asked about the barriers that she felt tend to hinder her from following the doctor's recommendations, Mary stated:

Umm don't have me started. How was I supposed to prevent all these issues I have now when everything is money. You wouldn't think that chronic disease should be free. No copays. Do you know how much I paid for the medicine and for checking my glucose when I followed what the doctor told me? It was a lot. It was costly to me. First, I was to see the doctor every month, but I stopped. Every time I went to the doctor just to monitor my pressure and sugar, I had to make copay. Right now I pay \$60 every time I see the diabetes doctor. Who wants to do that every month? I decided to make my own schedule either every three months or when I feel sick and the drugs don't help. And guess what I take my medicine only when I feel my sugar is high. Those drugs are not free you know. I pay \$30 for one drug that I take for a month and I take about 9 drugs. So I don't fill them every month. In addition to that I have to pay for my blood sugar supply. You know I am afraid of needles, but I use it as an excuse, not to take check my sugar. I can go to my sister's house any time to check my sugar for me, but I don't. When I think of the pain from the needle and the cost of the test strips, I ignore my sister's phone call. By the way I have to discard the test strips after use. Something that is not reusable cost so much. Diabetes is not cheap you know. It hurts your body and your pocket.

Like Mary, **Pamela** expressed her struggle with following doctor's recommendations due to medical visit copay for endocrinologist:

When my primary doctor referred me to see diabetes doctor, I only saw him once. I mean the doctor for diabetes. ... the amount of copay I was asked to pay was just way too much. Umm \$30. When I can pay only \$15 at my regular doctor's office. My friend is currently paying \$50 at her diabetes doctor's office who is the doctor I saw. My regular doctor is following my diabetes. I currently pay \$25, but I don't even see her regularly as she would like me too. I save on the diabetes supplies. I don't check my sugar at home anymore unless I feel sick. **Brenda** was a single woman at the time of her diagnosis. She later got to live with her ex-boyfriend and who moved out within 3 years. Her ex-boyfriend left her almost bankrupt, which made her already expensive diabetes treatment more expensive. Brenda stated that:

I went from being living with a man to living alone. I had to readdress my life on what I could afford. I would still have medication from previous year. My ex ran out my credit. Umm Pay check was taken for 10 pay periods. No extra money to help. Copay was the last on the list. I didn't go on my doctor's appointments. I didn't fill my medicine.

When asked as to whether she currently fill her prescribed medications since she does not have to pay back the debt her ex-boyfriend left her with, Brenda stated:

Those drugs cost an arm and a leg. I pay good amount of money at the CVS when I pick up them drugs. I don't fill them every month. I only take them when I feel sick and I don't feel my feet. I have diabetic nerve problems. I check my feet with a special object to feel and let doctor know. If I don't feel my feet, I take medicine. I can go months without filling my medicine. I think it is a combination of cost and laziness. I am my own barrier. I don't want diabetes.... I don't want to pay for diabetes.

The barrier **Eileen** experienced with the cost for treatment was unique from everyone else. She made sure that she kept all her medical appointments with the endocrinologist until the doctor could not take her health insurance. I used to see this old White guy.... Diabetes doctor. He was nice until he stopped accepting my health insurance. For every visit then, I had to pay \$200.... \$200 every month was too much for me. So I stopped going to this doctor. This is when I started developing some problems. I mean... I mean full blown diabetes. There were no other specialists in my town. Rockland County is small. Now they have many diabetes doctors everywhere in Rockland.

Unlike everyone else, **Esther** narrated her financial difficulties in regards to purchasing healthy foods. As per Esther:

The other issue I had.. Umm, Have you ever seen the prices for fruits? I believe the fruits are the most expensive foods. I really don't understand why healthy foods are expensive. I couldn't afford them sometimes.

Like everyone else, Esther struggled with making copays for doctor's visits and filling prescribed medications, and purchasing diabetes supplies for checking blood glucose levels:

It is very difficult for me to follow up with the specialist because of the amount of the copay... Umm \$50. I am paying \$50 a month and sometimes \$100 a month depending on my sugar level at the time of the visit. Sorry for being vague. My diabetes doctor sometimes has me follow up every two weeks. That is when my sugar level is high at the time of the appointment, while sometime I am developing a complication. I mean like my blood sugar is high, my legs are swollen. Filling those prescriptions is also not easy. I take two drugs plus get my supplies from Rite Aid. They cost me money you know. I feel like I go to work to

pay for my diabetes treatment. This is one of the reasons for not taking my medicine and not checking my sugar when I am supposed to. Those strips and needles are very expensive.

John did not refer to the cost of treatment as a barrier.

#### **Theme 5: Neighborhood Effect**

Participants in this study reported experiencing various form of stress related to the environment they live and work at. Consistent with literature review, **Esther** described her fear of walking in her neighborhood alone:

When I first got diagnosed, my husband walked with me. He was out of work. But he got busy when he went back to work. I got discouraged from walking. The neighborhood was not that safe. You take a walk and you don't know if you are going to be an innocent victim of gun violence. Just walking in the neighborhood. Not even proper path to walk. At least I currently reside in a neighborhood with walking paths and several gyms. There were no gyms in my former town. Or maybe there were, I didn't see them.

Esther was the only participant who discussed fear of walking in the neighborhood. Others including Esther discussed neighborhood stressors such as lack of fresh food and restaurants that make healthy foods, which is consistent with the literature review section. Esther stated:

The other problem I had, the vegetables, and fruits in nearby stores were not that fresh. I am very picky when it comes to greens. They have to be clean and fresh for me to buy. We had non-American restaurants and fast food restaurants...

Mexican, Haitian, Asian. The only problem is that these restaurants don't serve healthy foods.

**John** did not express much about the neighborhood effect. When asked about environmental barriers:

My issue is me. I could go and walk by my parent's house. They have a great walking path, bicycle path. My neighborhood, to think about, back then I lived in the city. I didn't see a path for walking, but I could have walked on the streets. My wife brought fruits, but they could get rotten in a day. I am not sure where she bought them, but that store had no quality fruits.

**Mary** described how she struggled with maintaining doctor recommended diet due to having no companion to cook for and restaurants in her neighborhood cooking foods that are not good for:

Laziness prevent me from cooking at home, ever since my daughter went to college. I now eat out at restaurants. I walk to the restaurants close to my home.... McDonalds, KFC, Chines. I buy fried plantains in a restaurant, Hatian, close to me. For food to be good in these restaurants, they have to cook something that is not good for you.

When asked to describe some of the barriers that prevent her from following the diets recommended by her physician, **Brenda** referred to her neighborhood:

You know it is difficult to change what you eat when you are raised in an environment where fast food is the order of the day. I am surrounded with all kinds of fast food places. I ate well when I lived with my ex-boyfriend and when I had my nephew live with me. After work, I don't feel like cooking, I just stop at a place and get food. Usually fast food restaurants close by me. Them fried fish umm chicken are going to kill me. I occasionally pick up Chines food from a restaurant by me. I choose these restaurants because they are near my home and fast to serve. I don't have the patience to drive 5 miles to a sit down in restaurant when I am hungry.

Despite working so hard to maintain the doctor's recommended diet and physical activities, **Eileen** reported that her neighborhood was one of the barriers that contributed to her diabetes complications:

It is kind of hard with the environment when people get shot outside. You can't go out there and start walking or jogging in the neighborhood. I had to move out of that neighborhood once I was able to put my daughter through college. I bought a house in a safer neighborhood. You know Black people have unhealthy food in their neighborhood. With no money, we tend to eat cheap and we don't know what we are eating.

Pamela was the only participants who had nothing to discuss about her neighborhood. She referred to her health behaviors and cost of medical treatments as her major barriers.

#### **Theme: 6 Juggling Work and Family Related Stress**

Several participants reported having experienced stress at work that elevated their blood glucose level and their blood pressure. **Mary** reported that she used to work during

the day, but had to change her shift to overnight to reduce stress of working with supervisors.

I like to take my time while performing tasks and I easily get tired. When I worked day shift, I used to get in trouble with my supervisor. She would yell at me for being slow with med pass. Oops I mean giving patients their medications. She got upset with me when she saw me sit in between administering meds. You know with my body weight and this thing diabetes. I tire quickly and can't move faster. I really got overwhelmed and upset most of the time at work. My pressure and sugar goes up whenever I get upset. I switched to overnight shift. My sugar and pressure got better than when I worked in the day. Umm I do see those supervisors for one hour in the morning, but they don't bother me like they used to. However when they do their rounds and discover a task I didn't do to their expectation, I get a memo. I mean disciplinary write up. My sugar and pressure are usually up when I get home after the write ups. Interacting with the patients is sometimes stressful. From being called the N word to being told that I cannot take care of them because of the color my skin. The patients themselves dictating who to care for them. Sometimes I am assigned to the most racist patient that ruins my night the minute I walk into their rooms. I was very upset the last time I worked. I overheard one of the patients conversation with the charge nurse. He was telling the charge nurse not to assign the N fat woman to his room again. This really broke my heart. I was very angry and my pressure was off the roof. My sugar was high too when I got home that day. Work stress bothers me. I know it because I

have good reading when I am off from work... vacation does me good. For example, I have been on out on leave for months now and my sugar is stable. My sister checked yesterday before I ate the chocolate that her husband sneaked to me. I am not sure of what to do when I get back to work. My doctor told me that the overnight shift is not helping me. Umm because of binge eating. I get bored at work when patients are a sleep, so I eat. When home, I don't eat past dinner time.

Like Mary, **Brenda** has a demanding job. She is a manager at a mental health facility. Dealing with her employees, patients, and her work load wears her out by the time she get home. Brenda reported that the stress at work contributes to her unhealthy lifestyle in regards to her diet:

I do not cook after a stressful day at work. I just stop at a place and get food. It elevates a lot of stress. My job is challenging. I get overwhelmed at work. Between problems with my staff, patients and what I am expected to do..... I get stressed. When I get home, my blood sugar is high. The stress of bouncing up and down, sometimes missing lunch. When I get home, I get upset for allowing this to happen. I need to say STOP, get nourishment.

As previously noted, **Eileen** is a divorced single woman who had to work 2 full time jobs to pay for her diabetes treatment, take care of her daughter, and to put her daughter through college. She did work so hard to stay healthy, but the stress at work and working two jobs sometimes took a toll on her. When discussing barriers that prevented her from following the doctor's orders and recommendation, Eileen expressed her jobs as one of the barriers: Juggling two jobs and being a single mother weighed me out. I could not take time off work to seek medical opinion when I first started experiencing the symptoms leave a lone well visits. I ate junk food between the two jobs. Sometimes I went the whole day without eating. Umm not good for me. The doctor told me I have to keep my blood sugar at a certain level. Sometimes the work load I was assigned would not allow me to go out and buy food. If I didn't bring food with me, then I had to snack on the junk from the vending machines. I got stressed.... All the work I had done to stay healthy just went down the drain while I was at work. I think this is how I developed other problems. My sugar would be high on the days I went to work. I had no time to go the gym. I got exercise from work by walking from one area to another while performing my duties. I now take walks daily, especially now that I am retired. My sugar has been stabilized from eating healthy at home. I am stress free. I wake up and go for walks in the Mall. Sometime I volunteer at a school serving lunch. I feel good. It is good to retire. Umm I can now take care of myself.

When asked about barriers that he perceived to have prevented him from following the doctor's recommendations, **John** had this to say:

It's me. I had all the opportunities to prevent and fight diabetes. I worked one job, though late hours sometime. I had two children, my wife basically took care of them she was a stay home mom. Started working when I was told I had diabetes. We thought I was going to die. Someone had to work take care of my girls. I had the time though. I think I got overwhelmed with managing the disease. My stress
was me. My mother helped babysitting, taking the kids to activities. I didn't have a stressful life. I got lazy and did not take care of myself.

Like Eileen, **Esther** worked two jobs. In addition to having two jobs she is mother of 6 children that she had to take care of and drive to extra curriculum activities. When asked the recommendations she received from the doctor, Esther reflected on stress at work:

I didn't know how I was going to get time to exercise. I had already had 2 stressful jobs... And with my children having so many activities in school. I was thinking loud at my first diabetes doctor's visit. My boys played soccer, football, basketball. My youngest daughter was a cheer leader. I didn't have time for exercise. I went back to work after being in the hospital and back to eating fast food.. pizza, hamburger between 2 jobs. My sugar was high so was my pressure. I felt comfortable because I had insulin with me. I didn't have time to exercise between my two jobs and my children activities. Yes, my husband couldn't help taking the kids to those activities. He worked long hours and came home late. I had not time to cook, exercise, pick my children up and sleep before the next shift. I worked 8 in the morning to 3pm first job then overnight shift from 11pm to 7am second job. Working overnight is not easy you know. My sister tells me that overnight shift caused the diabetes, she is crazy. Sometimes I think she is right. It so because my pressure and blood sugar got a little lower when I stopped working the shift. I am looking to retire soon. Remember my boss who had diabetes, her levels have been okay since she retired. I can't take the stress at the

job anymore. Do you really want to know what stresses me at work? ... everything. From the assignments to noisy coworkers to supervisors putting pressure on me. This is not good for my health you know.

### Theme 7: Need for positive motivation and support

Participants related their experience of what helped them to comply to the doctor's orders and recommendations. In their effort to stay healthy, the participants express needing someone to motivate and give them support. The participants used various ways to stay healthy, but needed reassurance from other individuals. All the participants wanted to be complimented of any progress they made, encouraged by others and social support system that ensures they live healthy life by adhering to physician orders. Consistence with literature review, some of the participants expressed needing support from their physicians rather than being blamed. For instance, **Esther** related her experience with the physician who informed her that she had diabetes as non-supportive:

The doctor at the hospital did not give me any hope. All he did was tell me to stop eating certain food.... I felt like I was being blamed for bringing, doing this to myself. I got really depressed and started eating even the foods I never used to eat. It was tough on me. I didn't know where to start. He sent me to see endo, that is the diabetes doctor. He did not provide recommendation apart from insulin. I started talking to people about my diabetes. I did research online. My son printed the information for me. I didn't use the internet. My husband became my hero. He encouraged me to stay strong to cope with the illness. He expressed to me how much my children needed me. As a matter of fact my family support changed my life. My husband exercised with me. We walked together in the neighborhood.

Reading articles retrieved from the internet was beneficial to Esther. Following up with endocrinology as recommended at the ER, was helpful as well. The endocrinologist provided her with several recommendations to assist her to maintain a good blood glucose level. Before all these, Esther's coping strategy was depression and food. She reported having change her lifestyle based on the encouragement she received from the endocrinology and support from her family and coworkers. However; Esther reported that her endocrinologist did not provide ongoing support which was discouraging to her. When asked what she thought her physician could do differently to help her, Esther responded:

Compliment me. When I bring down my sugar numbers... My doctor does not acknowledge when my numbers are good. He does not encourage me to do things differently. That is an eye opener. Thank you for asking that question. I need to have a long talk with my doctor. I stopped smoking. I used to smoke. I smoked for a while after finding out I had diabetes. I found myself quitting without his advice, my doctor's. Isn't that an achievement? When I mentioned to my doctor that I quit smoking, he did not have a positive reaction. All he said was "OK." You would think that he would be excited for me. Any way let me not go there. ... because that is a story for another day. I believe my doctor thinks I don't take care of myself. But I am trying. He does not believe in me. The good thing I believe in myself and I think I can do this, if I put all my strength and change my attitude. The good thing I have supportive family. My husband has gotten lazy since he retired. My oldest daughter walks with me sometimes. She visits two times a week and take me for walks. She sometimes pick me up to accompany her to my grandson's soccer game. We walk in the fields from one end to another when the kids are playing.

Esther also talked about her relationship with God and church members as support system.

Like Esther, **Eileen** had negative experience with her endocrinologist after the office stopped accepting her health insurance. Eileen felt discouraged with the lack of support from her physician, the one person she felt would ensure that she received the best medical care. When asked to explain barriers that she experience, Eileen stated:

Like I told you before, I worked very hard to do what the doctor told me to do, but was discouraged by the same doctor. When he could not take my insurance, he spent no time with me. I mean when I had my monthly appointments. Especially when he knew I had back payments. I owed them good amount of money. On one visit, this doctor did not touch me. Did not check my blood pressure.. a vital sign. No compliment or even advice. No, the nurse did not come to the room. The doctor read the blood sugar sheet that I brought with me. Did I tell you I had a blood sugar sheet that I chart my numbers? Okay. When I first saw this doctor, he gave me a sheet to chart my blood sugar every day and bring to the appointments. I stopped seeing that doctor. However, I got relapse. I think that is when I developed the problems. I decided that enough is enough and looked for a different doctor. Now I have a young doctor. He has been very helpful and taught me a lot. I have seen some progress in my health since then. I feel good about myself. I am encouraged.

As previously noted, Eileen is one of the participants who worked so hard to maintain healthy lifestyle despite some environmental and financial barriers. While discussing her coping strategies, Eileen referred to her family as her number one supporters:

My daughter is my cheer leader. She was a teenager when I found out I had this annoying disease. She was present when the nurse at the hospital was showing me how to check my sugar -and self-inject the insulin. She cried with me when I was down. My ex-husband did help too. He made sure I ate what was right for me and took my medications as ordered by the doctor. My brother checked on me daily through telephone conversations. He encouraged me and prayed with me. He occasionally would say "don't lose hope like mom did, fight it my sister, you are a strong woman." Yes my mother died of diabetes when I was about 5 years old and while my brother was ten. My aunt [mother sister] was there for me and still is. She brought fruits and fresh vegetables to me weekly for years. She is now elderly- in a nursing home. Yes my daughter continues to encourage me- plus her husband. They made sure they bought a house by me. Now that I am retired, my daughter picks me up few days a week to go for walks. Days that I don't go for walks in the mall. John reported that his social support system has helped him a great deal despite all the diabetes complications he currently has. When asked what has helped him to cope with diabetes diagnosis, John stated:

My family. My wife my hero. She has stuck with me through all the difficult times. Hospitalizations after hospitalization. Several ER and doctor's visits. She encouraged me to eat good stuff, but my stubborn nature got me to this stage. She walked side by side with me when I needed to lose weight. She checked my sugar level when she discovered that I lied, I already did. My mother has been present through this. She still is though living in a nursing. My children are now grown and helpful. Not to forget my coworkers. As I told you before, when I went back to work after being told I had diabetes, they were helpful. They educated me. They walked with me during lunch to help lose weight. I just messed up myself. I did this to me.

**Mary** depends on her family to encourage her and to ensure that she adhered to the doctor's orders and recommendations. Consistence with research findings in the literature review section, Mary is afraid of needles and depend on her children and sister to check her blood glucose level:

I am scared of needles. I do not check my sugar. I am not going to check it alone. I have to have someone do it for me. My children when they are home. Like I told you before, my oldest is married and live close to me. He stops by sometime and check it. But not frequent enough. My daughter in College check for me when she is home. My sister is my diabetes police. She tries to prevent me from cooking some foods-rice. When cooking for my son and my grandchildren, my sister always try to stop me from cooking the foods – knowing that I will be left with leftovers to eat. She tops at my house to check my sugar. She tells me what to do when the numbers are off. I told you she is a doctor. She lectures me when she discovers that I have not been taking my meds. One thing I like about my sister is that she will praise me when my numbers are good. That motivates me a lot. My brother, from London calls to check on me every week. When he visits, he makes sure that he live in my house to monitor me. I live in an a small apartment. You think he would prefer to live in my sister's big home- no. he says he want to monitor me. He is a doctor too. I am very lucky to have them. I do pray too. I pray that it does not get worse than it is. I feel sad- because my life is not the same anymore.

**Brenda** expressed that her family, friends, and church members have contributed to her coping strategies and helped ensure that she follows the recommended treatment regimen. Based on her personal experience with diabetes, Brenda posited that African Americans depends on family support and religious beliefs for survival and to cope with any bad news:

Us Black fox need each other. Our families knows how to come together when one of us is in need. You know that say "it takes a village to raise a child." I feel like a child ever since I got diabetes. From the moment I found out that I had this so called diabetes, my sister sent my nephew to live with me. He was in high school then. My sister wanted me to have a companion and someone to look forward to cooking for. This meant a lot to me. But little did I know he was sent to spy on me. I mean watch what I ate. My sister would call us every day to ensure that I checked my sugar and took my pills. My nephew would count my pills daily and report to my sister. I didn't know until when my sister confronted me with a list of days I didn't take my medicine. She would also ask what we had for dinner on the days I got fast food. I would not dare tell her the truth, but she would call me out.. "liar, you had Chines food today." We would then start fighting over the phone. Few minutes after hanging off the phone, she would show up at my house and apologize for trying to help me. We would then hug each other and cry. Not to forget, my cousins and girlfriends have been there for me as well. They are my motivators.

Brenda went on discussing how each friend and members of her church has supported her over the years. From assisting with purchasing diabetes supplies to receiving fresh fruits and vegetables from these individuals own gardens. Brenda further expressed her gratitude to the women in her church and her pastor. She reported having lost faith in God due to not being able to get married and her battle with diabetes. "At the beginning I asked God, why me? My church family came to my rescue." In other words, Brenda had given up on God, but members of the church helped renew her faith. Brenda is now convinced that her faith in God, family, church members, and friends have made her survive diabetes despite the complications she has. "if it was not for faith, I would be dead." Although Pamela reported having had family and friend's support, she did not attribute social support to her adherence to the doctor's orders and recommendations. She mentioned having helped Brenda by encouraging her to follow her treatment regimen. Her husband has been supportive, but Pamela focused on her resilience nature as her survival skills. When asked about natural support systems that have contributed to her adherence to the treatment regimen, Pamela had this to say:

It's me. I trust my doctor. Whatever he tell me, I do. I find this to be helpful. I was young when I got diagnosed with diabetes. A lot of Black people do not want to know if they have anything. They don't want to know if the doctor find them with a problem.. they can fix the problem. A lot of African Americans need to know about diabetes. It is not as bad as they think, if they take care of themselves. They need to be educated, diabetes don't kill- if you take care of yourself. I have been taking care of myself. Yes, I know about the problems I have, caused by diabetes. But I have survived for many years. Because I have followed what the doctor told me to do. Mostly what not to eat. He never told me what to eat, but what not to eat. I listen to my doctor.

As social cognitive theory point out, an individual's behavior is influenced by the environment in which the individual resides. This includes but not limited to people, condition in which one lives, human activities, and geographical area.

#### **Research Questions and Answers**

This phenomenological study was guided by one central research question (RQ1): what is it like for African American adults with chronic illness associated with diabetes navigating factors that contributes to racial ethnic health disparities. There were four secondary research questions (RQ 2, RQ 3, RQ4, and RQ5).

- RQ 1: What are the factors affecting the lives of African American adults with chronic illness associated with diabetes?
- RQ 2: How does the experience of African American adults with diabetes complications affect their health behaviors?
- RQ3: How does African American adults with chronic illness cope with diabetes complications in regards to their environment?
- RQ 4: What strategies to African American adults with diabetes complications use to cope with their diagnosis and adhere to health care providers recommendations?

The interview questions were guided by the research questions. The responses to the participants interview, the themes and the interpretation that emerged from the data analysis generated the answers to the research questions as follows.

# **Research Question One**

What is it like for African American adults with chronic illness associated with diabetes navigating factors that contribute to racial ethnic health disparities? The participants communicated their perspectives and experiences in terms of personal health behaviors, environmental factors, physical distress, social support system, stress associated with diabetes management, treatment cost, stress related to work and family obligations. The participants related their experiences to internal and external barriers that prevented them from managing their diabetes.

As reflected in the 7 themes, the participants experienced pain and suffering while navigating social determinants of health, which may have led to their worsened glycemic control, increase risk for complications and severity of the disease. Majority of the participants perceived the disease as something that can be controlled, but the cost for treatment is overwhelming and determined their diabetes outcome.

### **Research Question Two**

What are the factors affecting the lives of African American adults with chronic illness associated with diabetes? The participants perceived and interpreted 3 factors that affect the quality of their lives (a) Diabetes management and Treatment (b) Physical distress, and (d) financial cost related to diabetes.

**Diabetes management and treatment**. Individuals with diabetes must learn how to regulate their blood glucose level, participate in physical activities, monitor their food intake for glycemic control, and take their prescribed medication. Changing daily routine and lifestyle of eating and exercising in a drastic manner was challenging to some of the participants. The selection of food and food portion seemed to be the hardest part.

Although every participant's life was unique, all the participants expressed that diabetes management has affected the quality of their lives in regards to their ability to function. The many demands of diabetes management seemed to have been burden to all the participants. Mary stated, "I feel overwhelmed by continuously making sure that I have followed the routine of checking my sugar and eating what I am supposed to eat based on the numbers." She seemed very frustrated making this statement. Likewise, John reported 'I get overwhelmed dealing with diabetes. Sometimes I have to stop what I am doing to check my sugar level... and decide when to take insulin or when to get something to eat." Although Pamela felt confident in adhering to doctor's orders, she had this to say, "it becomes overwhelming to use blood sugar readings to make decision about what to eat when I have variety of food in front me." Regardless of an individual being well informed of diabetes and adhering to doctor's orders, diabetes management affect the quality of life.

The quality of the participants' lives depended on their diabetes management styles. The participants who reported being overly overwhelmed with the diabetes management and treatment regimen had diminished self-care. Mary, John, Esther, and Brenda increased their risks for diabetes complications due to overwhelming demand of diabetes management and self-care. According to Mary, "my doctor informed me that my diabetes could be managed, and I could prevent kidney problems. Umm but I didn't manage it well." Mary developed complications faster than it was expected by her endocrinologist. She reported being overwhelmed with checking her blood glucose levels due to fear of needles, not taking her oral medications as prescribed and not following her exercise regimen Esther reported:

Managing diabetes has destroyed my life. This is a demanding disease. When my kids were young, I was running around dropping and picking them up from activities, I had no time to manage this disease. I got depressed. I used the insulin a lot. I ate what I was no supposed to eat. Here I am with all the problems that this disease caused me.

The participants who had negative attitude towards their self-care did less than the requirement for managing diabetes, which affected their lives. John perceived the quality of his life as poor stating "taking care of myself has affected my physical, social, and emotional well-being." Brenda avoided checking her blood glucose level and taking her prescribed medication that could have delayed diabetes complications of kidney disease, vascular disease and nervous system disease. Based on the participants' account of their treatment regimen, diabetes treatment is intense. Eileen reported that her quality of life is worsened when she received her treatment regimen. She stated "the quality of my life has worsened. From making sure that I change my diet, taking pills daily, sometimes three times a day, to injecting myself with insulin, no life left in me."

**Physical distress**. Based on the result of this study, in addition to emotional wellbeing, physical well-being is important for individuals with diabetes to manage the disease and maintain long-term health. Consistence with literature review, individuals with diabetes quality of life regarding physical functioning is poor as compared to the general population. All the participants reported being physically distressed due to diabetes related complications.

Mary provided a perfect example of physical distress related to diabetes complications. "the pain on my nerves sometimes prevents me from doing anything. My muscles get weak, and sometimes I completely lose my sensation." Mary sometimes missed work due to her nerve pain. She was out on medical leave at the time of the interview. She reported "my nerves have been hurting me lately, I took off from work until they can get better." Mary's nerves affect her job performance as well as previously reported. "I walk slow, it take me long to administer meds to the patients." John, Esther, Pamela and Brenda reported similar experience with the nervous system disease. **Esther** had this to say about her struggle with the vision problems that she developed due to diabetes:

My eyes bother me a lot. I feel like I am getting blind. I see a doctor and receive treatment. Both my eyes get injected. I can't drive for 48 hours once the treatment is done. This was difficult for me when I worked. No I couldn't schedule the appointments on my off days. The doctor is in that office once a week on Wednesdays. I worked Wednesday nights through Saturday nights. Yes I missed 3 days of work per month. I think this is the reason they made me retire.

Several participants expressed the physical distress with checking their blood glucose level. John stated "I procrastinate using the device on my finger to get the blood... that thing is painful. Imagine doing that three times a day. The thought of the pain and the amount of blood I loose every day.. ugh is frustrating you know." Brenda revealed her struggle with physical pain of hyperglycemia and hypoglycemia. She reported "when I get home after work, my blood sugar is high. Sometimes low from missing lunch. My body feel weak, and I start shaking." Mary reported that the pain on her body made her realize when to take her medications.

**Financial cost related to diabetes**. Based on the participants' account of living with diabetes, this study found cost of managing diabetes to be a burden to people living with diabetes despite their socioeconomic status. The largest component of the diabetes management expenditure included hospital inpatient care, prescription medications to

treat diabetes complications, diabetes supplies, and copay for physician office visit. To effectively treat diabetes, all the patients were referred to see specialist, endocrinologists. However, the patient co-pay for specialist visit was a double or more than double of the amount of co-pay the participants pay at their primary care physician. For instance, the cost for Pamela to see a primary physician is \$15, while a specialist is \$50.

Although Pamela was financially stable, she described her struggle to pay for the cost of treating diabetes. As Pamela stated "when my primary doctor referred me to see diabetes doctor, I only saw him once, the amount of co-pay was way too much." Pamela reported having no issue financially, but could not pay endocrinology for a treatment plan that her primary physician could offer. Of all the participants, John endured more financial expenses. He has had a great number of ER visits, been hospitalized, and take about eleven medications to treat his diabetes complications. The cost for treating ulcers on his feet and legs then eventually amputation of both legs affected John a great deal financially. While sobbing, John stated:

My legs have cost me a lot of money. From treatment with creams and oral medicine, to lots of ER visits and hospital stays. This disease has me broke. I would love to stay home and have a nurse come take care of me. I would pay out of pocket. But no... I have to stay in this nursing home so Medicaid can pay for everything.

The cost of diabetes supplies was concerning to all the participants. The supplies include blood glucose test strips, and monitor, Lancet device and lancets, glucose control solutions, therapeutic shoes and shoes inserts. The cost of these supplies prevented the

participants from using them as prescribed by their physicians. For instance, Brenda reported, "I don't want to pay for diabetes." While Esther reported "these are one of the reasons I do not check my sugar when I am supposed to."

### **Research Question 2**

How does experience of African American adults with diabetes complications affect their health behaviors? Doctors often recommend for individuals with diabetes food selections and physical exercise regimen to prevent or delay diabetes complications. The participants in this study reported having to change their daily routine and lifestyle as part of their diabetes management plan. The health behaviors of the participants depended upon their belief and perception of the severity of the disease, self-control, time management.

Beliefs and perceptions of the disease. Each participant narrated their experiences with diabetes and health behaviors based on their knowledge of the disease at the time of the diagnosis. Eileen, Pamela, and Brenda changed their health behaviors at the beginning because they considered the consequences to be loss of their lives if they did not change their life styles. Eileen's physician who informed her about the disease was supportive and provided her with information that gave her hope. Eileen left the doctor's office with a belief that she would die if she did not follow the recommendations. As noted earlier, Eileen explained "my doctor told me diabetes could lead to kidney problems, would damage my liver, heart attack, gum disease…umm I want to live." At the beginning, Eileen changed her diet, eliminated smoking, and attended diabetes class. Eileen thought she had everything under control and deviate from the healthy diet to her old lifestyle. She developed complications. Likewise, Pamela and Brenda changed their lifestyle at the beginning when they believed they could die from diabetes complications. After hearing success stories, the two ladies beliefs about the disease changed and thus the complications. However, they are currently monitoring their food intake.

Esther, John, and Mary were in disbelief that they had diabetes. The three participants reported identifying with emotion of fear of death and dreaded changing their lifestyle. They did not know of any individual with diabetes and any individual surviving diabetes at that time. They continued with their lifestyle because they did not think doing so would change their lives as noted by Smilth et al (2011) health belief model. By not changing their health behaviors right away, Esther, John, and Mary increased their risk of developing diabetes complications. The three participants changed their health behaviors once they became aware of diabetes survivor's and realized the benefit of having healthy diet. Esther blamed her doctor for not giving her hope at the beginning. "the doctor at the hospital told me I had full blown diabetes. The doctor at the hospital did not give me hope." As a result, Esther initial belief was that would die of diabetes regardless of any effort she made. Upon reflection, all the participants beliefs have changed over the years to more of needing to concentrate on their self-care in regards to what they eat.

**Self-control**. The ability to self-control themselves in regard to their diet was a protective factor that helped keep blood glucose levels of the participants close to normal range without causing hypoglycemia or hyperglycemia. When asked how her experience with diabetes has influenced her lifestyle, Pamela responded,

Listen to your body. Don't wait until it is too late. Take care of yourself. I stopped eating heavy things that raised my blood sugar. I got to know foods that elevate the sugar. I control what I eat. When the mouth and eyes want it, I say no. Sometimes it is difficult. I have learned over the years that self-control is important. I want to keep my numbers at a good level. I want the doctor to discontinue the medications.. he will not D/C. he says the levels will get higher.

John and Esther recalled a period when they did not practice self-control that increased their risk of diabetes complication. They both expressed the physical pain and emotional distress during that period. The two participants changed their health behavior based on their experience during that period. John recalled a period of several hospital visits:

there was a period when I was depressed and took some time from work. I believed it was about a month I requested to be out. I led a sedentary life during that period. I was not concerned about what I ate. I ended up in the ER on several occasions.. umm I eventually got admitted into the hospital. I stayed in the hospital for two weeks. I was out from work for three months. I have never been the same. This was an eye opener. If only I took control of myself and watched what I ate. Presently I watch what I eat, but it is too late. I can't reverse all these problems. I can't get my legs back.

## **Research Question 3**

How do African American adults with chronic illness cope with diabetes complications in regards to their environment? Consistent with social cognitive theory, the neighborhood environment influenced the participants diet, physical activities through availability of recreational facilities, restaurants, and grocery stores. The participants reported that their environment influenced their diabetes management and self-care.

**Environmental barriers**. Previous research shows that environmental barriers plays a role in African Americans lack of physical activities (Brondolo et al., 2010). Although the participants tried to alter their environment to cope with diabetes, social stratification had negative effect on them. When asked about environmental barrier that prevented Eileen from doing physical activities, she responded, "I couldn't with the environment where people get shot." Eileen did move to a neighborhood that had safer environment and good walking paths. Esther attributed her lack of physical activities during the early years of her diagnosis to the neighborhood she resided in. She walked with her husband when he was available. She stated that she did not walk alone due to fear of gun violence in her neighborhood.

Some of the participants recalled having the desire to eat healthy food, fresh fruits and vegetables, which were not available in their neighborhood. Mary, John, Brenda, and Esther expressed their concern about the fruits and vegetables in their neighborhood grocery store. John stated "my wife used to bring home non fresh fruits. The fruits would go bad in less than a day." Esther reported having difficulties selecting fresh vegetables and fruits at the grocery store then giving up and purchasing unhealthy foods. She reported "I didn't feel guilty because there were no fresh vegetables. Remember, I told you I am very picky when it comes to my vegetables." Esther used this as a coping strategy in regards to her neighborhood. Brenda and Mary referred to lack of restaurants with healthy food in their neighborhood as a barrier that prevented them from maintaining proper diet regimen as recommended by their physicians. Brenda recall being tired from work and needing something to eats from a restaurant. However, the restaurants in her neighborhood were fast food restaurants. She exclaimed "I wasn't going to drive 5 miles to a restaurant for food after a long day at work." Has noted previously, Mary has been living alone for a while, which make cooking a burden for her. She prefers to pick up food from a restaurant, however, the restaurants in her neighborhood are fast food restaurants; McDonalds, KFS, Burger King, Chinese, Hatian, and DQ Grill and Chill restaurant. Mary had this to say "when I wake up in the morning, I want to just walk down the street and grab something to eat you know."

#### **Research Question 4.**

What strategies do African American adults use to cope with their diagnosis and adhere to health care provider recommendations? Coping strategies plays a key role in diabetes management that could prevent or delay the onset of diabetes complications. Each participant had unique experience with coping strategies. However, all the participants referred to their natural social support as their coping strategies and motivators for complying to the treatment regimen as prescribed by their physicians. Some participants reported adjusting their social roles to cope with the demands and challenges associated with diabetes. Pamela and Eileen attributed their compliance type of their personality. The following excerpts highlights the strategies that the participants used to adhere to their doctor's recommendations: **Esther**: My husband and children. My husband cleared our food pantry of junk food. My family encouraged me to eat healthy. My husband walked with me. My daughter is walking with me presently. My church members support me. My work supervisor encouraged me when I revealed to her that I had diabetes. She told me that people survive diabetes. She made me change my attitudes towards my diet. **Eileen**: My will power. I am that kind of person that do not fall apart when I get confronted with bad news. My daughter is my cheer leader. My brother encourages me by telling me to fight the disease. He occasionally would say "don't lose hope like mom did, fight it my sister." My aunt brought fruits and fresh vegetable to me weekly for years.

**Mary**: I am not good at following the doctor's orders. My children when they are home check my sugar and ensure I take my pills. They watch what I eat. My sister is my diabetes police. She prevent me from cooking some food. She stops at my house to check my sugar. She tells me what to do when the numbers are off. My brother from London calls to check on me.

**Brenda**: my sister would call every day to make sure I check my sugar and took my pills. When I lived with my nephew, he would count my pills daily to make sure I took them and report to my sister. Not to forget my cousins and girlfriends. They are my motivators. My church members have supported me over the years. They have assisted me with purchasing diabetes supplies and gave me fresh fruits and vegetables from their gardens. **Pamela:** it's me. Whatever he [doctor] tell me I do. I have been taking care of myself. I have followed what the doctor told me to do.

### Trustworthiness

To ensure the transparency and trustworthiness of this study, credibility, dependability, transferability, and confirmability were used. I employed member checking, thick description, triangulation, and audit trail as recommended by Bowen (2009). As outlined in chapter 3, member checking was employed to establish credibility, thick description as transferability, triangulation for dependability, and audit trail for confirmability.

For this study credibility, member checking occurred during the initial interview, and follow-up interview after completion of transcribing the audio recording into word document. I clarified interview questions and asked probing questions. I followed up ambiguous responses with probing questions for the participants to ensure that the participants' stories/perspectives/experiences were accurately reflected on the notes and audio recording. After transcribing the audio recording and reviewing the field notes, I scheduled and conducted follow up interviews. Three of the participants participated in the follow up interviews face to face, while the other three were conducted on the phone.

Thick description was used throughout this study to ensure transferability. The thick descriptions provided detailed account of each participants experiences living with diabetes complications in the context of their social environment. This study employed the participants' voices through using direct quotes. Confirmability was established by creating the themes based on the data that was obtained from the participants. The audit

trail confirmed that the patterns, themes, and concepts were grounded in the data. Dependability was established though audit trails of all participants recorded interviews, transcriptions, the emergent themes, interview questions, demographic telephone questionnaire, and informed consent.

#### Summary

This study explored and investigated the factors that contribute to the poor health outcome of African American adults with chronic health issues related to diabetes complications. The study interpreted the meaning the participants assign to their personal experiences, attitudes, and perspectives in the context of racial ethnic health disparities. A sample of six African American adults with diabetes complications were recruited from Hudson Valley region in New York State. The participants were interviewed face-to-face using semi-structured open ended questions related to their past experiences with diabetes complications, and ecological barriers that challenged their health prior to and post receiving diabetes diagnosis. The interviews also gathered the strategies the participants use to cope with the diagnosis and comply with physician recommendations, and the consequences of the participants coping strategies. The interviews were audio recorded and field notes we collected. The participants perceived experiences with their environment, attitudes and perception of the illness, stress related to work and family responsibility, and cost of diabetes management, natural social support (families, religious groups, peers with diabetes, and health care providers) contributed to their diabetes management and well-being.

The study was guided by central research question: What is it like for African American adults with chronic illness associated with diabetes navigating factors that contributes to racial ethnic health disparities? Four secondary questions explored the factors that are affecting the lives of African American adults with diabetes complications, how the experiences affect the participants' health behaviors, coping strategies in regards to the participants' environment, and strategies the participants used to adhere to physician recommendations. The field notes and transcript were analyzed into codes and categories. Themes emerged from the analysis. Chapter 5 presents the discussion about the research findings, conclusion, and recommendations for future research. Chapter 5: Discussion, Conclusion, and Recommendations

The purpose of this qualitative, phenomenological study was to explore and investigate the factors that contribute to the poor health outcomes of African American adults with chronic illnesses associated with diabetes complications. This study was performed to address a significant gap in literature related to African Americans adults who have chronic health problem and have developed complications in spite having health insurance.

Six African American adults with diabetes complication who had health insurance at the time of the diagnosis to present were interviewed. The participants were recruited from the summer of 2015, and the interviews were conducted in the spring and summer of 2016. Data received from the in-depth interview were analyzed and interpreted. Eight prominent themes were discovered from the raw data: belief and perception of the illness, denial, attitude towards health behaviors, treatment cost, neighborhood effect, juggling work- and family-related stress, and need for positive motivation and support. The participants' lived personal experiences with diabetes complications manifested through the eight themes.

#### **Interpretation of the Findings**

In the overall results of this study, I confirmed various findings in the current literature concerning factors that contribute to the poor health outcome of racial ethnic minorities compared to the majority in the United States. For instance, researchers have showed that African Americans experience high rate of complications from diabetes, including HD, KD, stroke, amputation, and blindness as compared to the general population with diabetes (Gumps, 2012; Kirkman et al., 2012). All of the participants in this study reported having HD. In addition to HD, four participants had KD, five had ND, four had VD, one had amputation of both his legs, and one had problems with her eyes nearly going blind.

Regarding well visits, all of the participants did not have well visits prior to diabetes diagnosis and delayed seeking medical attention when they had medical symptoms. Brondolo et al. (2010) noted that minority individuals with medical symptoms of any health issues often face significant economic and social barriers that make them delay seeking medical attention in which appropriate diagnoses might be made. Although the participants in this study had health insurance, they delayed seeking medical attention when they had diabetes symptoms. According to the study findings, the participants did not have time to take off from work and could not work from home when they experienced the medical symptoms. Not seeking medical services in a timely manner is linked to chronic health complications (Quinn et al., 2011;Smith et al., 2011).

Perceived discrimination in the health care setting has been associated with poor health outcomes of African Americans (D'Anna et al., 2010; Ford & Airhibenbuwa, 2010; Lee et al., 2009). Consistent with research findings (Brondolo et al., 2009; D'Anna et al., 2010; Lee et al, 2009), I established that the more that minority individuals perceived provider discrimination and experienced poor unsatisfying interaction, the less the minorities used health services when needed. A majority of the participants in this study reported not receiving adequate recommendations, encouragement, and reinforcement from their health care providers. Consistence with Bock (2012) study, the participants in this study gained knowledge about diabetes through seeking information themselves from diabetes peers, and the diabetes peers provided the source of reinforcement for self-management behavior. Three of the participants reported feeling hopeless and depressed after the physicians who provided them with diagnosis informed them that they would die due to the complication, but did not provide any hope of surviving the disease. Two of the participants reported changing their lifestyle and having progress, but their physicians did not provide compliment or reinforcement. There is a need for diversity and sensitivity training among health care providers.

All of the participants in this study used natural social support system as one of the strategies for coping with diabetes and self-care. This finding is inconsistent with the literature review as researchers indicated a lack of social support as a barrier to exercising and poor dietary among African American with diabetes (Dutton et al., 2005). All of the participants reported receiving support from families, diabetes peers, church members, pastors, and coworkers. The participants relied on their social support system versus health care providers. Three of the participants made efforts to change their lifestyles based on the information they received from diabetes peers at work. Several participants relied on their immediate and extended families to assist them with adhering to healthy nutrition.

Regarding self-care, African Americans find self-care challenging because of the complexity of the daily regimen requiring them to make lifestyle changes, which includes monitoring blood glucose levels, exercising, diet and medication management, and stress management (Gumbs, 2012). The participants in this research study confirmed the

previous research findings. All of the participants expressed experiencing challenges with the daily routine and lifestyle changes at some point. Pamela's compliance to treatment regimen was consistence with SCT and Gump (2012) study that revealed that patients who have self-efficacy tested their blood glucose level frequently and adhered to frequency of their medications. African Americans struggle with medication adherence due to barriers such as insufficient education and affordability due to a lack of health insurance (Quinn et al., 2011; Shenoliker et al., 2006), which is inconsistent with my study findings. All of the participants had health insurance prior to diabetes diagnosis to present. The r participants reported copay cost for the medications as one of the barriers. The participants were prescribed a minimum of five medications. According to the study results, law makers should work with health insurance companies on the cost of the copays for medication for chronic health illnesses. Medication adherence is influenced by SES factors and an individual's knowledge, perception of disease severity, and expectation from treatment (Hawkins et al., 2015). A majority of the participants in this study reported managing their diabetes based on the knowledge they had at that time, their perception of the disease, and the outcome they received from adhering to their medication regimen. The exception was Pamela who received information from her doctor and was knowledgeable about the disease. Pamela reported that her occasional non-adherence to prescribed medication was due to copay cost.

Regarding maintaining appropriate diet, this study aligned with other study findings that lack of access to grocery stores that offer a wide variety of food at decent prices are a barrier to minorities with diabetes. Morland e al. (2002) noted that physical availability of food, distribution of food stores, and food services are barriers that make it difficult for African Americans with diabetes to achieve sustainable dietary changes that affect their risk for diabetes complications. Another finding consistent with the literature regarding dietary regimen is that fast food restaurants serving the less healthy foods are predominantly in African American neighborhood (Lewis et al., 2005; Morland et al., 2002; Powell et al., 2007). Krishnan et al. (2010) found a positive relationship between the frequent consumption of fast food restaurant meals and Type 2 diabetes. A majority of the participants in this study routinely ate at fast food restaurants prior to the diagnosis of diabetes and reported having been healthy with no medical condition until they started experiencing symptoms of diabetes. The only exception was Pamela who had other medical conditions and was already receiving treatments at her primary physician prior to receiving diabetes diagnosis.

In regards to physical activities, SES characteristics of neighborhood may affect a person's health status independent of an individual's SES (Dutton et al., 2005; Krishman et al., 2010). The participants in this study revealed that exercise is important; however, they had no quality walking path in their neighborhood. In addition to a lack of places to do physical activities, all of the participants pointed out a lack of time between their jobs and family obligations. Some of the participants who moved from their original neighborhood post diabetes diagnosis and complications reported feeling good about themselves because they had quality municipal recreational facilities that allowed them to take walks. The finding is consistent with the literature that behavior and dietary does affect individual health, but an environment can deprive African Americans from living a

healthy lifestyle, which puts them at a disadvantage of developing complications as high crime rates make it less safe for residents to spend time outdoor and to engage in physical activities.

### **Theoretical Framework**

This research was guided by two theoretical frameworks: SCT and HBM. In the SCT, Bandura (1986) defined an individual's behavior as a triadic, dynamic, and reciprocal interaction of the individual's personal factors, behaviors, and environment. The health behaviors of the participants in this study were influenced with the environment in which the participants' lived and worked and the participants' health behaviors, attitudes, and emotional status. In this study, the participants voiced their perspectives on the impact of the environment, health behaviors, and emotional status as factors infringing upon diabetes management.

In terms of the environment, all of the participants at the time of the diagnosis lived in neighborhoods that had no to poor quality municipal facilities, walking paths, and recreational facilities in public locations that prevented them from engaging in routine physical activities that may have put them at a high risk of diabetes complications (Dutton et al., 2005; Krishman et al., 2010; Lawrence et al., 2010). Some of the participants in this study voiced that environmental barriers played a role in their physical activities. The participants were faced with stress at their work place that they believed to have contributed to elevated BP and blood sugar. Individuals with jobs that make it difficult to balance work and family obligations experience high stress levels, which in turn influences their health (Hegreaves et al., 2011; Robert, 1999). Mays et al. (2007) reported that suppressed anger may be a risk factor for high BP. Mary's report of experiencing high BP when at work is in consistence with these findings.

Individuals who are overwhelmed with diabetes management have diminished self-care, which leads to worsened glucose blood sugar control and increases their risk for diabetes complications (Gumbs, 2012). The participants' personal health behaviors and attitudes influenced their self-care. The participant who had negative attitude towards self-care did less than they should do to manage their diabetes. These participants developed diabetes complications at a faster rate, which was consistent with present research findings.

Bandura (1986) advocated a position he referred to as reciprocal determinism, which emphasizes that, behavior influence environment and environment influence behavior. In other words, individuals environment plays a role in the individual's behavior, and individuals behaviors plays a role in the individuals environment. Although individuals can change their environment, social stratification has negative effects on African American neighborhoods in regards to a lack of recreational facilities, grocery stores, and safe environment (Brondolo et al., 2009; D'Anna et al., 2010; Khang, 2010). The participants in this study were faced with external negative factors that they could not control. The participants reported that their experiences living with diabetes made them want to live a better lifestyle, but the external factors were unavoidable. Bandura further stressed that cognitive structures such as beliefs and expectancies influence and are determined by both behavior and environment, which led this study to HBM. .

The HBM is used to predict an individual's behaviors based on the theory that an individual's willingness to change health behaviors is primarily due to perceived susceptibility, perceived severity, perceived benefit, and perceived barriers (Smith et al., 2011). The participants in this study did not believe they could have diabetes; hence, some of them continued to be in denial despite receiving the diagnosis from medical doctors. Brenda and Mary continued with their health behaviors although they were warned by health care providers that they were at risk of developing diabetes, which confirmed the HBM notion that an individual does not change health behaviors unless the individual believes that he or she is at risk of developing a problem (Smith et al., 2011). According to the HBM, individuals take health actions based on the degree of perceived threat. Smith et al. (2011) maintained that an individual will change his or her health behaviors to avoid consequences if the individual consider the consequences to be serious, which they referred to as perceive severity. Some of the participants in this research study changed their health behaviors at the beginning when they perceived that if they did not do so, then they would develop complications and die. However, Esther and John did not change their lifestyle right away in spite acknowledging the severity of the disease. Both of the participant lacked knowledge due to insufficient education on diabetes and having no knowledge of any individual who survived diabetes.

An individual will change behaviors if the individual know that he or she will benefit from the change (Smith, 2011). Although all the participants in this study reported knowing the benefits of following physician recommendations, the cost of the copays of medications and diabetes supplies acted as a barrier to their compliance with prescribed medication regimen. Perceived barriers were experienced by the participants in terms of copay cost of medical treatment and a lack of health promoting resources, such as healthy food and facilities for physical activities. No participants reported behaviors of others in the community or social cycle as perceived barriers to their lifestyle post the diagnosis. All of the participants reported having a natural social support system.

## Limitations of the Study

The purpose of this qualitative, phenomenological study was to investigate and explore the factors that contribute to racial ethnic health disparities through in-depth experiences of African Americans with diabetes complications. Every effort was made to ensure that the study was credible and trustworthy as outlined in Chapter 4. The first limitation was the sample recruitment. The samples were recruited via flyers placed in endocrinology offices and different locations that are frequented by African Americans. None of the participants were recruited at the doctors' offices, which could have verified that the participants actually had diabetes. There was no means of verifying that some of the participants had diabetes except for the participants who had physical symptoms, such as swollen lower and upper extremities and eczema on their skins. Two of the participants were recruited via the flyers while the rest were snowballed into study. External validity may have been limited due to the sampling bias.

The second limitation is that homogenous six African American adults with diabetes complications and had health insurance may not be representative of all African Americans with other chronic health problems. Third, the participants were asked to reflect back on their lives prior to diabetes diagnosis and post the diagnosis to present. The participants self-reported their stories and may have selectively remembered the events or forgotten the events. In other words, the participants did not provide data to corroborate their stories; therefore, I presumed the participants to be truthful in telling their experiences with diabetes. The fourth limitation was that there was no inquiry to the participants' SES. I presumed that individuals with long-term health insurance were at a better SES. The fifth limitation was that I intended to discover factors that lead to poor health outcome of minorities; however, the study was limited to African Americans. Therefore, the study cannot be generalized to all minority groups.

#### **Recommendations for Future Research**

The purpose of this study was to explore the factors that contribute to poor health outcomes of racial ethnic groups in order to identify interventions to mitigate racial ethnic health disparities. Based on the findings of this study, additional recommendations for future studies were identified. The sample size of the participants in this study was only six African American adults with diabetes complications who had health insurance at the time of the diagnosis to present. As documented in the literature, a gap exists in qualitative studies relative to the experiences of minorities with chronic health issues who have health insurance. Although studies of health disparities within the U.S. population consistently show that African Americans have higher all-cause of health mortality rate and low life expectancy (Bock, 2012: D'Annn et al., 2010; Hicken et al., 2012; Zheng & Schimmele, 2005) due to little or no health insurance (Quinn et al., 2011), the gap continues to exist. The prevalence of Type 2 diabetes in African Americans adults is twice as much as non-Hispanic Whites (Bertera, 2003; Cheng et al., 2012). For example,

the ADA (2014) reported that 13.2% of African Americans have a Type 2 diabetes diagnosis as compared to 7.6% of non-Hispanic Whites. Future research into the experiences of racial ethnic groups should include a larger sample and should inquire about their experiences with medication, diabetes supplies, and specialists' copays.

This research study suggested that among the African American participants studied, there were potential disparities in medication adherence and compliance to medical appointments post the diagnosis. Future research should focus on exploring the different types of health insurance and socioeconomic status to provide some explanations for the difference. Another recommendations for future research is to investigate the difference in compliance to various type 2 diabetes medications and if the difference exists among minorities with and without health insurance. Furthermore it is crucial to know if the participants who were not taking their medications were more likely at a higher risk of developing further complications. With this information, future research should access the participant medical records to obtain all the diabetes complication diagnoses, list of medications, and the participants' Hba1c. Future research should also access the participants' pharmacy records to get accurate information whether the participants fill their prescribed medication in a timely fashion or not.

### **Implications for Social Change**

Racial ethnic health disparity is social problem because the health of the minorities influences the health of the nation, which in turn affects the nation's economy. According to U.S Census Bureau (2010), minorities are expected to make 50% of the US population by 2050, which augment the importance of researching and addressing racial

ethnic health disparities. Research shows that African Americans and other minorities experience worse health outcome than non-Hispanic Whites due to social determinants of health and health insurances (D'Anna et al., 2010; Hargreaves et al., 2011). The social determinants perspectives inequalities in social, environmental, economic, and physical conditions influence and deprive the minorities opportunities for healthy behaviors such as access to healthy food, access to health care, and physical activities facilities (Brondolo etal., 2009; D'Anna et al., 2010; Ford & Airhihenbua, 2010; Hargreaves et al., 2011; Kahng, 2010; Kim et al., 2010; Robert , 1999). Therefore, any recommendation that can impact the ability to mitigate racial ethnic health disparities, promotes social change.

America has moral obligation to ensure health equity for all especially the most disadvantaged population based on the notion of social determinants of health (Kim et al., 2010). However, research does not show whether the ethical arguments have been effectively communicated to the public law makers. Based on this study findings, eliminating or mitigating health disparities require strategies that modify environmental conditions (Prevention 2002). This research can influence policy makers to develop environmental factors such as safe incidental and or recreation physical activities, and safe affordable healthy foods within the disadvantaged population neighborhoods. In other words, the current health policy addressing health disparities could be more effective if socioeconomic inequalities in the neighborhood characteristic is incorporated into the policy. There is a need for policy makers to work with insurance companies in
regards to co-pays for specialists, medications for chronic health issues, and diabetes supplies.

The findings from the study illustrated that some participants felt discriminated by the health care providers when the providers did not give them the needed information for self-care and/or when the provider did not motivate and complimented them for any progress they made. This finding revealed a need for culturally competent intervention to reduce discrimination in health care providers' offices. According to Lee et al., (2009), culturally concordant patient-physician matching can help reduce health disparities. There is a need for policy to address educating health care providers in sensitivity and diversity to encourage minority patients to utilize health care facilities. Perceived health care provider discrimination has been linked to poor health outcomes (Lee et al., 2009); therefore, educating the providers could play a role mitigating racial ethnic health disparities.

The results of this research revealed that diabetes management is time consuming. The participants reported poor self-care due to the overwhelming nature of the diabetes management. However, they received support from their families, friends, coworkers and church members. Based on the finding, self-care intervention should be tailored to offer diabetes patients necessary skills to seek education on diabetes, and establish routine for monitoring schedule (Chlebowy et al., 2010). The intervention should also include patients social support network. The social network that are identified by the patient need to be educated about diabetes self-management and provided with the necessary information and resources to assist the patient with diabetes manage the treatment regimen. The information and resources should include self-managing blood glucose level, medications, and adherence to physical activities and dietary recommendations. Public health professionals and other human services professionals like social workers can intervene by helping individuals with diabetes manage the care and social barriers related to diabetes.

### Conclusion

This phenomenological qualitative study explored the experiences of six African American adults with chronic health issues associated with diabetes complications. The participants shared their personal stories of living with diabetes, which revealed that the cost of copays for diabetes medications, supplies, and specialist visits acted as a barrier for their compliance to treatment regimen. Findings from this study demonstrated that behavior and dietary affect African American health, but environmental and social circumstances deprive them from living healthy lifestyle despite having health insurance. The participants in this study were very emotional and suffered physical pain associated with diabetes complications.

The participants in this study have endured a great deal of health issues and have learned to live with the disease. Each of the participants have mastered unique coping strategies and have received a great deal of support from their social support system. Although individuals with diabetes receive services from health care providers, as agents of change, professional social workers and other human services professionals must develop culturally relevant interventions to help individuals living with diabetes overcome diabetes related barriers.

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#### Appendix A: Consent Form

This informed Consent is for African American adults with diabetes complications who are invited to participate in a research on Racial Ethnic Health Disparities.

## Introduction

My name is Florence Okombo. I am working on my PhD at Walden University. I am completing research on racial ethnic health disparities which is a growing public health problem. Racial ethnic health disparities refer to the differences in health status, life expectancy, and many other indicators of health in different racial and ethnic groups. You are invited to participate in this study. You do not have to decide to participate right away. Please feel free to discuss the research with someone you feel comfortable with prior to making your decision whether to participate or not. The decision of whether to, or not to, participate in the study is up to you. This informed consent may contain information that you do not understand. Please ask and I will take time to explain the information you do not understand.

#### **Purpose of Research**

Research shows that racial/ethnic minority groups experience more health issues than non-minority Whites in the United States of America. I would like to find ways to mitigate or eradicate health disparities among racial/ethnic minorities. You are being invited to participate in this research because I feel that your experience as African American with diabetes can contribute to my understanding and knowledge of the personal and ecological barriers that affect the health of minorities. I believe that you can help me by discussing about your personal health experiences with living with diabetes. I would like to explore the personal experiences, attitudes, and perspectives of African American adults with chronic health issues related to diabetes complications. I want to learn about the different ways that African Americans try to follow doctors' recommendations and to manage and stop diabetes complications. This knowledge might help me to learn how to reduce health problems in minority community.

### **Inclusion Criteria**

The participants must be African American adult at least 18 years of age; must have diabetes with complications; must have had some type of health insurance at the time of diabetes diagnosis; must live in Hudson Valley Region in New York.

# **Data Collection**

This research will involve your participation in face-to-face interview with me that will take one hour. I will sit down with you in a comfortable public place in a library, or a Café of your choice. The interview can also take place in another public place of your choice if it is better for you. No one else, but myself will be present, unless you would like someone else to be present. I will ask you to respond to open ended questions. I will write down and record your entire responses during the interview and follow up incomplete answers. Please feel free to ask for clarification if you do not understand any question. I will also record the interview with your permission. The information recorded will be kept confidential and no one else will have access to the information documented during the interview. No one will be identified by name on the tape. I will store the tape and the research documents in a locked safe. I will keep the information recorded

confidential and no one else will have access to the tape. The tapes will be destroyed after 5 years.

## **Research Participant Rights**

Your participation in this research is entirely voluntary. You can choose to participate or not or leave the study at any time. Choosing not to participate, or leaving the study will not lead to loss of benefit that you are entitled to or any penalty. This researcher may also stop the study or remove you from the study at any time if I judge it is in your best interest. I may do so without your consent. However, you will still receive the benefit.

### Risks

The interview discussion contains some personal and sensitive issues that may make you feel uncomfortable. However, I do not wish for this to happen. I will ask you to share with me some confidential and personal in information. It is OK if you do not want to answer some of the questions or take part in the interview. You do not have to provide reasons for not answering any question or refusing to participate in the interview process.

## Benefit

Although you will not benefit directly from participating in this research, you will make major contribution to the information known about racial/ethnic health disparities. In future, other minorities like African Americans may benefit from the information you provide because doctors, other public health professionals, human services professionals and/or legislatures will learn about how to prevent, mitigate and eradicate minority health issues.

## Incentives

I will give you \$10 for your time and additional funds for your travel reimbursement.

# Confidentiality

All the information I collect from this research project will be kept private and confidential. Your name will not be used in any information about you. Instead, I will use number code and pseudo name, which will be kept in a locked safe. Only myself will know what your number is. All data files will be kept in a locked cabinet. The information kept in a computer will require a secure password to retrieve/open. Only this researcher will have access to the information obtained from the study.

#### **Sharing the Results**

The knowledge I get from this research will be shared with you before I make it available to the university and to the public. I will provide each participant with a summary of the results. Please feel free to provide feedback after carefully reading the study result.

## **Contact for Request or Problems**

If you have questions about the study, any problem, psychological discomfort, or any injury, you can contact Florence Okombo at 914-420-4639 or

<u>Florence.okombo@waldenu.edu</u> or contact Dr. George Ayers (Research chair) at <u>George.Ayers@waldenu.edu</u>. This proposal has been approved by Walden University Institutional Review Board (IRB) for ethical standard research, which is a committee that is responsible of ensuring that the research participants are protected from harm. If you wish to find more about the IRB and/or your rights as a participant, please contact IRB@waldenu.edu.

I will provide you with a copy of this informed consent.

Your Signature

\_\_\_\_

Date\_\_\_\_\_

\_\_\_\_\_

#### Appendix B: Research Flyer

My name is Florence Okombo. I am PhD student at Walden University. I am looking for participants for dissertation research on Racial Ethnic Health Disparities. I am hoping to discover common themes that impact the health of African American adults in order to find ways to mitigate or eradicate health disparities among racial/ethnic minorities. The participants must be African American adults with diabetes, must have had complications due to diabetes, must have health insurance, and must live in Hudson Valley region in NY (Westchester, Rockland, Dutches, Bronx, and Ulster counties). This will be face-toface interview that will be conducted indoor in a public place of your choice; for example, at Panera Bread Café, Starbucks Café, Library among others. You will receive monetary compensation for your time and transportation. I expect the interview to take 1 hr. I can be reached at 914-420-4639 if you are interested in participating in the interview or if you have any questions regarding participation. I can also be reached via email at <u>Florence.okombo@waldenu.edu</u>

#### Appendix C: Telephone Questionnaire

Hello, my name is Florence Okombo. Thank you for contacting me to inquire more about my dissertation project.

- 1. May I ask who I am speaking to?
- 2. Do you consider yourself as African American, White, Hispanic, Asian, or other?
- 3. Are you at least 18 years or older?
- 4. Do you currently have a diagnosis of diabetes?
- 5. Do you experience diabetes complications such as high blood pressure; kidney disease; heart disease; issues with your sight or hearing; and/or nervous system disease that cause pain in your feet or hands, slow digestion of food in the stomach, and carpel tunnel syndrome?
- 6. Do you have health insurance?
- 7. Are you interested in learning more about this study?
- 8. I will send to you a consent document that explains the research and your rights as a participant.
- Note that your participation is voluntary and you can change your mind at any time.
- 10. Please provide me with a few dates and times of your availability for the interviews. Or would you like me to call at another time to set up the interview after you receive the consent document?
- 11. What is the best way to send the document to you? Email or regular mail. I can also scan and send as a text.

12. What public place would you prefer for the interview to take place?

Thank you for participating in this telephone questionnaire. Please feel free to contact me with any question and/or if you change your mind on participation.

#### Appendix D: Interview Questions

- Prior to receiving the diabetes diagnosis, how often did you have well visits to a doctor?
- 2. Can you please describe to me some of the barriers that may have prevented you from receiving medical care as soon as you started experiencing the medical symptoms?
- 3. Kindly describe to me how you felt when you received a diagnosis of diabetes
- 4. What are the strategies that you are using to cope with diabetes?
- 5. What are the consequences of your coping strategies?
- 6. What were the medical orders and recommendations that you received from the doctor upon receiving the diabetes diagnosis?
- 7. What has helped you to adhere to these orders and recommendations?
- 8. Can you please explain to me the barriers that you feel tend to hinder you from following the doctor's recommendations?
- 9. What are the lifestyle changes that you made post diagnosis on diabetes?
- 10. Can you please describe to me the particular lifestyle change that you are experiencing challenges in following?
- 11. What are the challenges?