Learning and Playing the Game: Living with Structural Racism and Diabetes throughout the Life Courses of Older African Americans

A dissertation submitted in partial satisfaction of the requirements for the degree

Doctor of Philosophy in Nursing

by

Kia Nicole Skrine Jeffers

2016
ABSTRACT OF THE DISSERTATION

Learning and Playing the Game: Living with Structural Racism and Diabetes Throughout the Life Courses of Older African Americans

by

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Despite being a manageable chronic condition, type 2 diabetes is among the leading causes of death and disability in the United States. Of the 29.1 million people who have diabetes in the U.S., almost half are adults ages 65 years and older, and 39% of older African Americans have the condition. African American seniors are more likely to experience diabetes-related complications compared to other racial groups. These complications lead to end stage renal disease, non-traumatic lower extremity amputations, heart disease and premature death at two to four times the rates of their non-Hispanic White counterparts. This study utilized a constructivist grounded theory methodology to understand the potential relationships between African American older adults’ experiences with structural racism across their life courses, and their experiences with type 2 diabetes in older age. The author’s interpretation of the fit
between participants’ narratives about structural racism and diabetes was centered on the processes through which participants dealt with social- and health-related threats. The findings revealed narratives that clustered into three major constructs: Identifying Threats, Learning and Playing the Game, and Exercising Agency.
The dissertation of Kia Nicole Skrine Jeffers is approved.

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2016
DEDICATION

Naite, Sara, Uncle Allen, and Uncle William: I did it! Please get together in Heaven to celebrate! I miss you...XOXOX
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ACKNOWLEDGMENTS

I am first grateful to God, who kept me throughout all of the highs and lows that accompanied this doctoral journey. I am beyond grateful for my family—my husband, my children, my parents, my siblings, my godparents, and my extended family who have stepped in to support and encourage me, and to fill in the gap when I was away doing all of this.

I want to acknowledge my friends—my Girl Power sisters, my Mama-Sister-Friends, and The Circle of Seven crew—all of whom have been my lifeline at various parts of this experience.

My heartfelt thanks extend to: members of my PhD cohort—Wendy Johnson, Alexa Benson, Nancy Chang, Carol DeLilly and Bianca Gonzalez; the Pan-African Nursing Students and Alumni Association (PANSAA)—Rhonda Flenoy-Younger, Tonia Jones, Ariel Rankin, Lindsay Williams, and Tiffany Montgomery…Thank you for helping to push me to the finish line!

My gratitude goes to: the UCLA Center for the Advancement of Gerontological Nursing Science (AGNS) Faculty—Dr. Phillips, Dr. Cadogan, Dr. Mentes, and Dr. Woods; the AGNS Students & Alumni—Maria, Carie, Michele, Sharon, Will, Adrienne, Hafifa, Stephanie, Cecile; and to the UCLA School of Nursing Student Affairs and Leadership Team.

I deeply appreciate: my dissertation committee—Dr. Phillips, Dr. Cadogan, Dr. Haley, Dr. Heilemann, and Dr. Thomas; my interdisciplinary mentors—Dr. Chandra Ford and the Public Health Critical Race Working Group, and Dr. Catherine Sarkisian and the LA CAPRA team; my extended academic family—Dr. Ebere Ume and Dr. Shirley Evers-Manly; and my community colleagues—Phyllis Willis and the Freedom 101 Team.

I am thankful for the financial support that I have received throughout my doctoral education—Eugene V. Cota-Robles Fellowship, Jonas III Veteran’s Healthcare scholarship, Kaiser Permanente/Deloras Jones Scholarship, UCLA CTSI Summer Training Fellowship, UCLA RCMAR GSA Preconference Scholarship, and conference travel funds from the UCLA School of Nursing Research Office.

Last, but certainly not least—I am immeasurably thankful for my participants. I could have never done this without you. Thank you for sharing your lives with me, and for helping to open the door to my future...
VITA

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Chapter 1

INTRODUCTION

African American older adults’ (AAOA) experiences with structural racism and type 2 diabetes (T2DM) were the focus of this study. T2DM is a condition marked by elevated blood glucose levels due to impaired insulin production or activity (American Diabetes Association [ADA], 2016). To achieve and maintain adequate blood glucose levels, individuals with T2DM self-manage the condition through routine, long-term, biomedical and behavioral activities (ADA). Without adequate self-management, persons with diabetes often endure complications. These complications include kidney failure, nerve damage, eye disease, lower limb amputations, sexual and urologic dysfunction, or premature death (National Institute of Diabetes and Digestive and Kidney Disease [NIDDK], 2012).

In contrast to younger persons with diabetes, older adults face heightened risks of complications due to geriatric syndromes—including depression, cognitive impairment, sarcopenia, urinary incontinence, falls and fractures, persistent pain and physical frailty (California Healthcare Foundation/American Geriatrics Society Panel on Improving Care for Elders with Diabetes, 2003; K. Kim, S. Kim, Sung & Park, 2002). Also, older adults are often on several medications for multiple medical conditions. Polypharmacy increases their risks of experiencing drug interactions that most commonly lead to hypoglycemia, an uncontrolled diabetes condition (Kim et al.).

In addition to biologic and co-morbid considerations, older adults are faced with unique social factors that raise their risks for diabetes-related complications and early death. For instance, Zhang, Norris, Gregg and Beckles (2007) found that older persons
with diabetes who had lower levels of social support had significantly higher mortality risks. XinQi, Simon, Beck and Evans (2010) found significant associations between lower levels of health and social wellbeing, and greater self-neglect among older adults. Burnett et al. (2006) found that older adults with fewer social resources such as family, domestic partners or cohabitants, children or siblings, friends or religious communities were less likely to provide adequate care for themselves to maintain their health.

These problems can be particularly pronounced for some groups such as African Americans. Social factors that broadly affect older African American adults are often compounded by cumulative experiences with structural racism, discrimination, and unequal day-to-day treatment (Ford & Airhihenbuwa, 2010a; Smedley, Stith, and Nelson 2002). Evidence has shown that African Americans’ lifelong experiences with racism lead to poor health outcomes (Smedley, Stith & Nelson, 2002).

It is widely known that AAOAs are experiencing excessive rates of diabetes-related complications. They are dying prematurely, losing their limbs and eyesight, and experiencing kidney failure at two to four times the rates of their white counterparts (Office of Minority Health [OMH], 2015). Researchers have noted that even if African Americans and non-Hispanic whites had similar exposures to psychosocial risk factors such as socioeconomic status [SES] and education level, differences in outcomes persist (Williams & Leavell, 2012).

Some have attributed the disparities in complications among AAOAs to race. In fact, researchers have found a genetic link that predisposes African Americans to developing diabetes. Known as the “thrifty gene,” Neel (1962) noted that this genotype is “exceptionally efficient in the intake and/or utilization of food” (p. 354)—which
historically served humans well during times of feast and famine (Neel, 1962). Researchers in the field of epigenetics have recently found that individuals with diabetes remain at risk for vascular complications despite achieving normal blood glucose levels due to a phenomenon called metabolic memory (Reddy & Natarajan, 2012). Evidence has shown that vascular cells that have been exposed to hyperglycemia predisposes individuals with diabetes to retain their pro-inflammatory diabetic phenotype long after achieving glucose control (Reddy & Natarajan). This is due to persistently increased levels of oxidative stress and inflammatory genes (Reddy & Natarajan, p. 435). Evidence shows that “African Americans have higher levels of oxidative stress than Whites, even after adjusting for [disease-specific] risk factors and inflammation” (Morris et al., 2012, p. 252). Again, psychosocial factors impact differences in outcomes for persons with similar physiologic exposures.

Recent evidence offers an alternative explanation of differential risk for complications between racial groups. This explanation is centered on the psychosocial realm—particularly as it relates to race. Many claim that it is not a biological determinant (Braveman, Egerter, An, & Williams, 2011; Jones, 2000; Relethford, 2009; Williams, 1997; Wong, 2008). Despite distinct global patterning of phenotypic variations in skin color and craniometric traits between humans, Relethford noted that race is “a culturally imposed label that crudely and imprecisely describes real variation” (p. 20). It does not account for the wide range of geographic origins, cultural norms and practices, or historical backgrounds of people who simply look alike.

As a social label, race also positions individuals for differential social experiences. Williams (2001), in The International Encyclopedia of the Social and
Behavioral Sciences, described race as reflecting “differential exposure to health-related risks or resources” (p. 4831), and that race is “a central determinant of social identity and obligation, as well as of access to societal rewards and resources” (p. 4832).

According to Jones (2001), race reflects the degree to which individuals experience racism. Gee, Walsemann, and Brondolo (2012) noted that racial classification not only reflects potential exposures to racism, but also to health inequities. These conceptualizations offer a different look at race from a diabetes-related research perspective. “Race” is usually considered a demographic variable that is operationalized as internal to the individual, as opposed to being externally imposed. “Race” is also often associated with low socioeconomic status, lack of adherence, and poor quality of life when describing African Americans with T2DM—as opposed to being associated with the social structures and experiences with social systems that have led to these psychosocial and behavioral outcomes. Such a limited characterization undoubtedly disadvantages African Americans. Jones (2000) noted that without mining for more informative clues within the greater social context, scientific knowledge suffers—particularly as it relates to health and in addressing health disparities.

Several researchers have connected the dots between race, racism and health. Williams (1997) aimed to examine what race is, and to identify specific risk factors and resources that were associated with race that might explain variations in health between racial groups. As a complex construct, Williams noted that race reflects a wide range of biologic, geographic, cultural, social and racism-related factors. According to Williams, these factors combine to affect health and healthcare utilization.
Researchers have considered the associations between race, racism and health for several conditions. For example, using Critical Race Theory, Ford and Airhihenbuwa (2010b) linked racism-related exposure to a negative impact on the HIV testing choices of African Americans. Lekan (2009) and Mullings (2005) used the “Sojourner Syndrome” to disentangle the intersectional consequences that race, gender, and class have on health outcomes. Geronimus, Hicken, Keene, and Bound (2006) proposed the “weathering” hypothesis which posits that the cumulative impact of perpetual experiences with social or economic adversity and political marginalization leads to early health deterioration for African Americans. “The weathering effects of living in a race-conscious society may be greatest among those Blacks most likely to engage in high-effort coping” (Geronimus, Hickman, Keene & Bound, p. 826).

Researchers labeled high effort coping as John Henryism, to explain the connection between prolonged, cognitive and emotional engagement with psychosocial stressors such as career issues, health problems and racism over many years, and African Americans' increased risk for morbidity and early mortality (Duke, 2006; James, 1994; Neighbors, Njai & Jackson, 2007). Researchers have noted evidence of John Henryism among African Americans with hypertension and sickle cell anemia. It also has been well-established that there are associations between being African American, having lifelong experiences with racism, and hypertension. These works lay the groundwork for what is a significant gap in the literature related to race, racism, and diabetes self-management among AAOAs.
Statement of Problem

Despite being a manageable chronic condition, T2DM is among the leading causes of death and disability in the United States (National Center for Chronic Disease Prevention and Health Promotion [NCDPHP], 2016). Of the 29.1 million people who have diabetes in the U.S., almost half are adults ages 65 years and older (Centers for Disease Control and Prevention [CDC], 2014), and 39% of older African Americans have the condition (Administration on Aging [AoA], 2015). African American seniors are more likely to experience diabetes-related complications (OMH, 2015). These complications lead to end stage renal disease, non-traumatic lower extremity amputations, heart disease and premature death at two to four times the rates of their non-Hispanic White counterparts (CDC; OMH). According to the CDC and NCDPHP, the death rates may be modest estimates since diabetes often leads to chronic mental and physical conditions that eventually result in death. Consequently, diabetes is undoubtedly responsible for, but not identified as, the cause of significantly more deaths (CDC; NCDPHP).

Recent evidence shows that an individual’s choice to engage in diabetes self-management activities may be derived from psychosocial factors (Wagner et al., 2011; Walker, Smalls, Bonilha, Campbell, & Egede, 2012). Existing literature frequently describes the psychosocial factors that inform diabetes self-management in terms of self-efficacy, self-management knowledge, quality of life, diabetes distress, patient-provider interactions, coping styles, problem-solving (Amoako, Skelly, & Rossen, 2008), psychological wellbeing, treatment adherence, social support, access to care, education, and socioeconomic status (; Beverly et al., 2013; de Rekeneire et al., 2003;
Fitzpatrick, Schumann, & Hill-Briggs, 2013; Hausmann, Ren, & Sevick, 2010; Peyrot et al., 2005). These studies have yielded mixed results in explaining relationships between psychosocial factors and inadequate diabetes self-management among AAOAs (Haussman et al.). What appears to be missing is an examination of the external social context within which AAOAs reside, and the ways in which AAOAs’ experiences within their social contexts inform their self-management behaviors.

According to Gale’s Encyclopedia of Medicine (http://medical-dictionary.thefreedictionary.com/psychosocial, 2008), psychosocial is “a term referring to the mind’s ability to, consciously or unconsciously, adjust and relate the body to its social environment”. Burke et al. (2009) noted the opportunity that studying the social environment provides to better understand influences on individuals’ behaviors. AAOAs have been uniquely situated within social environments, and have faced social barriers that may impact their self-management behaviors differently than other racial/ethnic groups (Ford & Airhihenbuwa, 2010a; Haussman et al., 2010). As such, research shows that coping and problem-solving styles differ between African American and White populations. Given the differences in how today’s cohort of AAOAs and White older adults have been positioned within social environments throughout their lives, it is plausible that disparities in diabetes outcomes are grounded in psychosocial factors that are closely tied to their life-long social environment. This association has been largely unexplored in the literature.
Significance

The estimated national cost of diabetes in the U.S. in 2012 was $245 billion (ADA, 2015). The economic burdens associated with diabetes include rising direct medical costs ($176 billion) and indirect work-related costs ($69 billion) (ADA). The effects of pain, suffering, and reduced quality of life for individuals with the condition, their families and friends are increasing as well (ADA, 2013a).

Health resource utilization related to diabetes status

According to the ADA (2013a), there were a projected 168 million hospital inpatient days incurred by persons with and without diabetes in the U.S. in 2012. One-quarter of those days were incurred by individuals with diabetes, with more than half (26 million) of those days directly attributed to diabetes. One-third of the total nursing/residential facility days were incurred by individuals with diabetes, with half of those days attributed to the condition. Of the 174 million outpatient physician visits made by people with diabetes, almost half were due to the disorder. This is consistent with the rates of emergency department (ED) and hospital outpatient visits as well. Of the 15 million visits to the ED, 7.3 million visits were specifically diabetes-related; and, nearly 8 million of the 15 million hospital outpatient visits were directly due to diabetes. More than half of medication prescriptions for people with diabetes—including insulin and other antidiabetic agents—are attributed to the condition.

With regard to health resource utilization that was directly attributed to diabetes, compared to individuals 0 to 64 years, individuals 65 years and older utilized 63% of the hospital inpatient days, 80% of the nursing/residential facility days, 57% of the physician office visits, 42% of ED visits, 43% of the hospital outpatient visits, and 60% of the non-
diabetes medication prescriptions. Individuals 45-64 years narrowly lagged behind the older age group with diabetes-specific ED visits (36%) and hospital outpatient visits (41%). In contrast to non-Hispanic whites who have the highest per capita use of nursing home/residential facility, physician office visits, and prescription medication use, non-Hispanic blacks have the highest utilization of hospital inpatient, ED, and hospital outpatient care (ADA, 2013b).

**Health care expenditures attributed to diabetes**

Health care expenditures attributed to diabetes are costs that are in excess of expenditures that individuals would have incurred if they did not have diabetes (ADA, 2013a). A majority of the costs are due to the higher rates of hospital admission and longer average lengths of stay per admission (ADA). According to the ADA, almost 60% of the health care expenditures attributed to diabetes in the U.S. are for individuals ages 65 years and older. Diabetes-specific costs total $104 million within this age group, and consist largely of hospital inpatient days ($48 million), prescription medications—excluding insulin and antidiabetic agents (almost $19 million), and nursing/residential facility days (almost $12 million). Data suggest that persons with diabetes incur almost $8000 in additional expenditures per year per person. Per capita, the estimated average annual excess expenditures for individuals ages 65 and older with diabetes are almost $12,000. For African Americans, diabetes-specific expenditures exceed other racial/ethnic groups per capita due to their higher utilization of hospital inpatient, emergency department (ED), and hospital outpatient services (ADA).
Health resource utilization related to diabetes complications

A considerable amount of health resource use is attributed to chronic diabetes-related complications. Cataracts, cellulitis, conduction disorders and cardiac dysrhythmias, general medical conditions, heart failure, hypertension, myocardial infarction, other chronic ischemic heart disease, renal failure and its sequelae, and urinary tract infection are the ten medical conditions that contribute the largest costs associated with diabetes (ADA, 2013a, p. 1035). Metabolic complications account for 44% of ED visits and 41% of hospital inpatient days; peripheral vascular, cardiovascular, renal and neurological complications account for 36%, 35%, 33%, and 31% of hospital inpatient days, respectively; and, cardiovascular and neurological complications each account for 23% of ED visits (ADA, 2013b).

Health care expenditures attributed to diabetes complications

Chronic complications of diabetes cost a substantial amount. In 2012, over $19 million in hospital inpatient services were attributed to chronic cardiovascular complications, over $4 million to chronic neurological complications, nearly $4 million to chronic renal complications, and almost $3 million to chronic peripheral vascular complications (ADA, 2013a). Per hospital inpatient day, chronic cardiovascular, peripheral vascular, and neurological diabetes-related events cost $3,741, $2,898, and $2,881, respectively (ADA, 2013b). The most costly ED visits were incurred by chronic metabolic ($1,385), cardiovascular ($1,077), and peripheral vascular ($903) events.
Indirect costs

Indirect costs associated with diabetes include work absenteeism, presenteeism (i.e., attending work while sick and unable to fully perform job responsibilities) reduced labor force productivity, reduced productivity for those not in the labor force, and premature mortality (ADA, 2013a; Widera, Chang, & Chen, 2010). Total indirect costs in 2012 were estimated at $68.6 billion in the U.S., with the greatest burden coming from reduced labor force productivity due to permanent disability ($21.6 billion), presenteeism ($20.8 billion), and premature mortality ($18.5 billion).

According to the ADA (2013a), individuals with diabetes are 2.4% more likely to leave the workforce early due to diabetes-related disability. The highest per capita indirect cost associated with productivity loss between racial groups was experienced by African Americans (ADA, 2013b). Non-Hispanic blacks exceeded non-Hispanic whites in their rates of reduced productivity due to not being in the labor force, and in their rates of unemployment from disability. These factors have significant psychosocial implications.

Researchers contend that AAOSAs exceed other racial groups in their rates of diabetes-related complications (American Diabetes Association [ADA], 2016), health resource utilization, healthcare expenditures, and in reduced productivity (ADA, 2013a). Researchers also maintain that psychosocial factors are a likely contributor to these excessive rates (Williams & Leavell, 2012). Some researchers have found that lifelong experiences with racism and other social barriers have negatively impacted the health statuses of AAOSAs (Gee et al., 2012; Williams, 1997). Although researchers have identified pathways through which race and experiences of racism influence health
(Brondolo, Gallo & Myers, 2009), no studies have identified a link that connects race, structural racism experienced throughout the life course, diabetes self-management behaviors and diabetes complications. This study is designed to explore more deeply the social environments that have shaped the diabetes self-management behaviors of AAOAs.

**Purpose of Study**

The purpose of this study was to develop a framework for understanding the ways in which the self-management behaviors of African American older adults (AAOAs) with uncontrolled type 2 diabetes are related to the racism-related experiences, particularly structural racism-related barriers that they have encountered throughout their lives. The aims of this study were:

1. To describe structural racism-related experiences that AAOAs with uncontrolled T2DM have endured throughout their lives.
2. To identify the personal meanings that AAOAs with uncontrolled T2DM ascribe to structural racism-related experiences.
3. To identify meanings that AAOAs with uncontrolled T2DM ascribe to their diabetes and diabetes self-management.
4. To generate a theory that is grounded in the narratives of AAOAs with uncontrolled T2DM that explains the relationship between lifetime experiences of structural racism and uncontrolled diabetes in older age.

The researcher used a qualitative approach to develop this framework—specifically, a constructivist grounded theory (CGT) methodology. Constructivist grounded theory was appropriate because it provided a rigorous, inductive method for
exploring relationships between structural racism and diabetes self-management among African American seniors, and for theory generation.

**Implications for Health Care Providers**

This study lays the groundwork for the development of community-based, nurse-led interventions to empower AAOAs with inadequate diabetes self-management behaviors. By understanding the impact that structural racism-related factors have had on the lives of AAOAs, we have a better idea of how to appropriately intervene. This study also adds to the growing body of research that addresses structural racism’s role in the health disparities literature. No other studies were found that examine the relationship between structural racism and diabetes self-management among AAOAs at the time of this study.

Note: Self-management and self-care are used interchangeably in the literature. For the purposes of this study, the term “self-management” will be used to describe individuals’ diabetes-related behaviors.
Chapter 2

CONCEPTUAL ORIENTATION

Although the use of conceptual frameworks in knowledge generation lends itself to quantitative research, grounded theorists are guided by sensitizing concepts, which lay a foundation for a study (Charmaz, 2006; Bowen, 2006). Blumer (1954, p. 7) described the utility of sensitizing concepts as giving “the user a general sense of reference and guidance”; and, Charmaz (p. 259) described them as “background ideas that inform the research problem…. [and] as a way of seeing, organizing, and understanding experience”. Bowen also noted that sensitizing concepts are useful in laying a foundation during data analysis. My work was influenced by Symbolic Interactionism (SI) (Charon, 2010), the Social Determinants of Health (United States Department of Health and Human Services [U.S.DHHS], 2012), concepts from the Life Course Perspective (Alwin, 2012; Gee et al., 2012; Giele & Elder, 1998; U.S.DHH, 2010), and Structural Racism (Bonilla-Silva, 1997; Powell, 2007).

Symbolic Interactionism

The philosophical underpinning of grounded theory is in Symbolic Interactionism (SI) (Aldiabat & Le Navenec, 2011). Symbolic Interactionism considers individuals as active in their environment, and interactive with both themselves and others (Charon, 2010). SI supported my aim to understand how AAOAs’ diabetes self-management behaviors have been shaped through the social interactions they have encountered throughout their lives. Symbolic Interactionism also helped guide my understanding of the psychosocial processes that inform the meanings that AAOAs ascribe to those social experiences. As described by Aldiabat and Le Navenec (2011), SI provided the
lens through which I conceptualized my participants’ self-management behaviors in relation to the social circumstances, rules, politics, and conditions that have surrounded their lives. Of particular relevance were the concepts of the self, objects, and society.

**Self**

According to SI, there are two parts to the self—the “I” and the “Me”. The “I” is the uninhibited, spontaneous, uncontrolled part of the self; and, the “Me” is the socially-constructed self (Charon, 2010; Mead, 1934). Mead describes the “I” as the “un”socialized, human part of self. It is the part of the self that has not been influenced by the social environment. In contrast to the “I” is the “Me”, which is influenced by the attitudes, expectations and interactions with “Generalized Others”—e.g., individuals, social groups, community, and even social class (Mead, p. 154). These “Generalized Others” inform how the “Me” part of the self behaves (Aldiabat & Le Navenec, 2011). Given the influence that “Generalized Others” have on the “Me”, the “Me” controls the uninhibited “I” part of the self from the “Generalized Others’ ” point of view. Through internal conversations between the “I” and “Me”, the “Me” quiets the humanness of the “I” with the attitudes, expectations and rules of the “Generalized Others”.

**Objects**

Blumer (1969) described objects as physical (e.g., a chair), social (e.g., friends), and abstract (e.g., moral principles). According to Blumer, the social interactions between human beings and their “generalized others” are based upon the social meanings of these physical, social, and abstract objects. Although Charon (2010) stated that social meanings are constantly changing as a result of ongoing human interactions,
Aldiabat and Le Navenec (2011) noted that “the social meanings of these objects are the most important predictors for human behaviors” (p. 1065).

Examining the physical, social, and abstract objects and the meanings associated with them was important in this study. It was imperative to understand, for instance, the influences that such objects as “Mr. Charlie”—i.e., white men regarded as oppressors to Blacks (Lighter, 1994), and Jim Crow laws (Pilgrim, 2012) in AAOAs’ early years might have had on the self-management behaviors in their later lives.

**Society**

Charon (2010) described two views of society—static and dynamic. This study was influenced by the notion of society as a static entity—i.e., as a structure with a historical reality that includes the development of institutions, stratification systems, and cultural patterns (Charon). Society as a static entity imposes its history upon individuals within the society. According to Charon, society shapes and socializes each individual, and the individual, in turn, internalizes society. While I recognized that symbolic interactionists’ view of society tends to lean on the side of society as a more dynamic entity—“a becoming rather than a being” (Shibutani, 1961, p. 174 as cited in Charon, 2010, p. 152)—and that there are individuals who are change agents within society, this study was grounded in the conception of society as being built upon a historical past that is deeply embedded in its contemporary structure.

**Pragmatism**

I also acknowledged pragmatism as part of the philosophical underpinnings for symbolic interactionism. According to Menand (2001), pragmatism is “an account of the way people think—the way they come up with ideas, form beliefs, and reach decisions”
Pragmatism focuses on people as problem-solvers in search of what works for them (Warms & Schroeder, 1999). This was a particularly salient understanding in terms of the individual truths of AAOAs, a group who has negotiated within and around structural and social adversity throughout their lives. Understanding the truths—the meanings—that they ascribe to their social worlds and diabetes, helps to deepen our understanding of the ascriptions they make about their diabetes self-management behaviors.

**Social Determinants of Health**

Whereas “determinants of health” describe factors involving biology and genetics, individual behavior, social environment, physical environment, and health services, “social determinants of health” pertain to the social structures and economic systems that are shaped by the distribution of money, power, social policies, politics and resources throughout communities (CDC, 2013). Social determinants of health include the conditions and circumstances within which individuals are born, grow up, live, work, and age, and the systems that handle illness (CDC). The social context within which AAOAs were born, grew up, have lived, worked, aged, and engaged with the health system determined a unique experience for this population, which in turn, has impacted their health (Smedley et al., 2002).

**Life Course**

Life course has been conceptualized as a theory, a concept, and a perspective (Gee et al., 2012; Giele & Elder, 1998; U.S.DHHS, 2010). Life Course Theory integrates social environment, personal characteristics, and the timing of experiences, to understand behavior (Giele & Elder). The theory connects the concepts of when and
where an individual is socially situated; the individual’s social interactions; the individual’s age at the time of their experiences; and how an individual sees himself or herself, and ultimately behaves. As a concept, life course is defined as "a sequence of socially defined events and roles that the individual enacts over time" (Giele and Elder, p. 22).

The life course perspective recognizes that an individual’s life history, and the transitions that occur at various life stages influence health-related attitudes and behaviors, and are shaped by the wider social context (Alwin, 2012; Giele & Elder, 1998). Life course is useful in examining the relationships between early- and later-life outcomes and experiences (Alwin, 2012). Utilizing a life course perspective was relevant to this study because it reflected an integrated continuum of exposures, experiences and interactions that was shaped by social institutions and sociocultural values, and informed later life behaviors.

Developmental Stages

Life course researchers have identified an overlap with life span development theory regarding the concept of age in that they posit that the level of social and personal meanings that individuals are able to derive from experiences are attached to their developmental stage (Alwin, 2012; Giele & Elder, 1998; Elder, Johnson, & Crosnoe, 2003). To provide a context for the developmental stages when this study’s participants described their life experiences, I have relied on the age delineations for life span development categories that were put forth by developmental psychologist Erik Erikson (1950). These categories are intended to provide a context for the developmental stages when half of my participants migrated from their home regions to
Los Angeles, and later in this chapter, to provide the developmental context shaping participants’ ascriptions when applicable.

**Erikson’s Eight Stages of Psychosocial Development**

Erikson’s eight stages of psychosocial development include: Infancy (ages birth to 18 months), Early Childhood (ages two to three years), Pre-school (ages three to five years), School Age (ages six to eleven years), Adolescence (ages 12-18 years), Young Adulthood (ages 19-40 years), Middle Adulthood (ages 40-65 years), and Maturity (ages 65 years to death) (Santrock, 2008). Since participants described experiences beginning at six years of age, I collapsed Erikson’s first three developmental stages into one category entitled “Early Childhood” which covers birth-five years of age.

Under the umbrella of “Early Childhood”, are years in which individuals learn to trust the world, when they develop a sense of control and independence over themselves and learn to assert power and control within their environment (Santrock, 2008). The School Age years are marked by the development of individuals’ self-worth (Santrock). Children are mostly influenced by schoolmates, and members of their neighborhood and community (Davis & Clifton). Adolescence is marked by the development of a sense of self, self-image, and personal identity. Adolescents are greatly influenced by their peer groups, out-groups, and role models during this stage (Davis & Clifton). Young adulthood is the developmental stage when individuals “lose” themselves, and learn to find themselves in friendships, a partner, spouse, or parent (Davis & Clifton). Middle adulthood is characterized as a time of creating one’s legacy, taking care of family, and contributing to the world that will live on beyond them. Finally, older adulthood is characterized as a time of reflection of one’s life. If individuals view
their lives as successful, they feel a sense of integrity. Conversely, if individuals view themselves as unproductive or unaccomplished, they feel a sense of despair, which often leads to a sense of hopelessness and depression (Santrock).

**Structural Racism**

Bonilla-Silva (1997) described structural racism based on two central ideas—racialized social systems and racial ideology. According to Bonilla-Silva, “racialized social systems are societies that allocate differential economic, political, social and even psychological rewards to groups along racial lines—lines which are socially constructed” (p. 474). Based on how these systems are structured, an ideology develops. Bonilla-Silva equated that ideology to what other researchers have coded as racism. In his view, this ideology “becomes the organizational map that guides actions of racial actors in society” (p. 474).

Powell’s (2007) conception of structural racism is in line with Bonilla-Silva’s (1997) in that he contends that a system’s structure gives rise to its behavior. Extending Bonilla-Silva’s conception of structural racism as racialized social systems and racial ideology, Powell (2007) emphasized the ongoing interaction between multiple systems, and that this ongoing interaction continually produces racialized outcomes. Powell noted,

At the level of societal organization, the structural model helps us analyze how housing, education, employment, transportation, health care, and other systems interact to produce racialized outcomes. At the level of cultural understanding, the structural model shows how the structure we create, inhabit, and maintain in turn recreate us by shaping identity and imparting social meaning (p. 793).
The conceptualizations of structural racism by Bonilla-Silva (1997) and Powell (2007) undergirded the aims of this study, which focused on the individual experiences of structural racism from the point-of-view of each participant.

**Summary**

As a qualitative investigation, this study was informed by a few, key sensitizing concepts that provided the foundation for this study’s research aims. Symbolic interactionism shaped the philosophical perspective that individuals derive meaning from the interactions that they have with themselves and others within their social environments (Aldiabat & Le Navenec, 2011; Blumer, 1969; Charon, 2010; Mead, 1934). These meanings inform individuals’ behaviors and their commitment to doing what works for them in their lives. Additionally, this study was informed by social determinants health—i.e., the conditions within individuals’ environments that shape their health and outcomes—and concepts from the life course perspective, which provide a link between early life social exposures to later life health behaviors (CDC, 2013). Finally, this study was informed by structural racism—the hierarchical arrangement of racial groups, and the distribution of resources and power that yield differential life chances and health outcomes between racial groups (Bonilla-Silva, 1997; Powell, 2007). These sensitizing concepts shaped my inductive approach to understanding the relationship between the participants’ ways of thinking about their lifelong social experiences and their later life experiences with diabetes and diabetes self-management.
Chapter 3

LITERATURE REVIEW

Dearth of Existing Literature

Lew, Nowlin, Chyun, and Melkus (2014) summarized diabetes self-management intervention studies led by nurse principal investigators. The authors conducted a systematic review of the literature in PubMed, CINAHL, and Web of Science. They used combinations of the search terms “self-care,” “self-management,” “education,” and “diabetes” to generate a collection of relevant articles. Their search resulted in 44 studies, ten of which were focused on all, or primarily, African American populations. Nine studies had sample sizes that ranged from 16 to 324 African Americans, and one pilot study sampled 21 participants. Among the ten studies, nine studies had participants with a median age at or above 50 years.

Only two studies were identified by Lew et al. (2014) as being “culturally-tailored”. Although the terms culturally-tailored and culturally-relevant have been operationalized in different ways in the literature, studies have demonstrated short-term improvements in participants’ HbA1c levels when diabetes self-management interventions incorporate cultural components. Additionally, the National Institute of Nursing Research (2011) has identified a focus on culturally-relevant self-management interventions as part of their strategic plan to eliminate health disparities between racial/ethnic groups. The findings from this State of the Science paper underscore the need for nurse researchers to attend to culturally appropriate diabetes self-management interventions.
The literature search for this study was conducted in PubMed using the search terms “diabetes self management” (n = 6,183 studies); “type 2 diabetes self-management” (n = 4,390 studies); “diabetes self-management interventions” (n = 835 studies); and, “type 2 diabetes self-management interventions” (n = 584 studies). Table 1 details the diminishing results found when adding the terms “African American,” “cultural,” and “older adults” to the search. A search of CINAHL using the same search terms yielded far fewer results (Table 2). Results from each database included systematic reviews, studies conducted within and outside of the U.S., in rural, suburban, and urban settings.

Table 1. PubMed Search of Literature containing Diabetes Self-Management, Type 2 Diabetes Self-Management, Interventions, African American, Cultural, and Older Adults.

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<th>“T2D SM”</th>
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Abbreviations: DSM=Diabetes Self-Management; T2D SM=Type 2 Diabetes Self-Management; AA=African American
Table 2: CINAHL Search of Literature containing Diabetes Self-Management, Type 2 Diabetes Self-Management, Interventions, African American, Cultural, and Older Adults.

<table>
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Abbreviations: DSM=Diabetes Self-Management; T2D SM=Type 2 Diabetes Self-Management; AA=African American
*Initial search did not yield any results. However, using SmartText Searching, these results were found.

As indicated in Table 1 and Table 2, there is a dearth of existing literature that addresses culturally-tailored self-management interventions aimed at AAOAs with T2DM. Due to the scant literature available, this review includes culturally-tailored intervention studies with middle-aged, and at times, young adult African Americans (Appendix 1).

Culturally-Tailored Intervention Dimensions: Surface Structure vs. Deep Structure

According to Resnicow, Baranowski, Ahluwalia, and Brathwaite (1999), interventions can be culturally-tailored within a surface structure dimension or a deep structure dimension. Surface structures are reflected in the observable social and behavioral characteristics of a study population. This includes matching such traits as the race, language, food preferences, and locations/settings preferred by the participants. For instance, culturally-tailored interventions geared toward African Americans might have African Americans and African American food preferences (e.g., soul food) displayed in the intervention materials. Surface structure refers to “the extent to which interventions meet target populations where they are; how well they fit within
their culture, experience, and behavioral patterns” (Resnicow, Soler, Brathwaite, Ahluwalia, & Butler, 2000, p. 273).

In contrast, deep structures incorporate social, historical, environmental and psychological factors that impact the health behaviors of the target population differently than other groups. These factors include religion, family, society, economics and the government, and their perceived or actual impact on the target population’s health behaviors. For the purposes of the organization of this review, a surface structural context entails the observable characteristics that meld into existing cultural life; a deep structural context is associated with structures, systems or deeply embedded beliefs that negatively impact health behaviors.

**Surface Contextual Factors Addressed by Surface Structural Dimension Interventions.** In the study conducted by Keyserling et al. (2000), the researchers noted a socio-cultural mismatch between available diabetes self-management intervention models and African American women’s needs. Their culturally-tailored intervention, “A New Leaf…Choices for Healthy Living with Diabetes,” utilized a mix of a community- and clinic-based interactions to improve dietary and physical activity behaviors. The sample was drawn from seven primary care clinics in central North Carolina, and consisted of 200 African American women, aged 40 years and over (mean age was 59 years), who on average had diagnosed diabetes for 10 years. Four counseling sessions were conducted in the clinic by a health counselor, followed by 12 telephone contacts by a community diabetes advisor (CDA), and three group sessions. CDAs provided social support and feedback to participants; reinforced diet and activity goals during monthly telephone calls; and, assisted with group sessions (Keyserling et
al., 2000; Norris et al., 2006). The CDAs focused on teaching the study population about decreasing saturated fat intake, carb spacing, and engaging in physical activity according to the participants’ preferences. The study’s researchers conducted 17 focus groups to evaluate the cultural relevance and acceptability of the intervention. Participants found “A New Leaf…Choices for Healthy Living with Diabetes” to be culturally relevant and acceptable.

Church has been a central institution for African Americans from the time of slavery onward (Collins-McNeil et al., 2012). Spirituality is deeply intertwined throughout many aspects of everyday life for this group (Polzer & Miles, 2005). Collins-McNeil and colleagues described church settings as “natural points of connection and social support” (p.128); and, Samuel-Hodge and colleagues (2009) noted that churches are an established institution for health promotion.

Given this cultural understanding, researchers have situated culturally-tailored interventions within these settings. But, the interventions just skim the surface of what appears to be deeper cultural issues. For instance, in the study conducted by Collins-McNeil et al. (2012), the diabetes self-management intervention was “culturally-tailored” based on the written materials, video tapes, and presentations by racially concordant health providers and research staff. Culturally-specific meals were used from the “New Soul Food Cookbook for People with Diabetes” for the healthy eating module. Participants also made a contract with program staff and clergy that stated their commitment to engaging in physical activity. Additionally, the healthy coping module included biblical stories, scriptural readings, prayers and songs. Despite significant increases in self-reported medication adherence, healthy eating and foot care
adherence, results indicated an increase in HbA1c from baseline to post-intervention. There were also no significant differences in physical activity or blood glucose monitoring.

Samuel-Hodge et al. (2009) conducted a church-based, culturally-tailored intervention entitled “A New DAWN (Diabetes Awareness and Wellness Network)” to improve the diabetes self-management behaviors of African Americans. A New DAWN utilized a Church Diabetes Advisor (CDA); however their role was dissimilar to the CHWs described previously. CDAs in this study were trained in motivational interviewing techniques, listening skills, DSM, and telephone counseling. They were not community/system navigators like in the previously described studies (Cummings et al., 2013; Keyserling et al., 2000; Two Feathers et al., 2005). The culturally-tailored intervention also consisted of an individual counseling visit with a dietician, 12 bi-weekly group sessions, and four monthly phone calls from the CDA. Although the aims of the study included deep structural factors, the culturally tailoring of this intervention was limited to a surface structural characteristic—i.e., the location in which the study took place. The researchers aimed to not only promote individual change in the diabetes self-management behaviors of the participants, but also to enhance physician-directed care, and to build the capacity of the participating churches to increase the diabetes awareness within the church communities. Results of “A New DAWN” indicated significant HbA1c changes at eight months, but not at 12 months.

Melkus et al. (2010) utilized a primary care setting and an adjacent school of nursing to implement their culturally-tailored diabetes self-management intervention. The researchers posited that the lack of culturally relevant interventions in clinical care
settings was contributing to the growing problem of health disparities among African American communities. To address this deep structural issue, the team utilized culturally specific materials that focused on cultural barriers and beliefs that inhibited healthy dietary intake and ideal body weight. These materials included a handout entitled “Soul Food Celebration,” which provided recipes for modifying culturally preferred foods; a culturally-specific video, “Put the Fat Back;” and, culturally-focused cookbooks--the “Black Family Dinner Quilt Cookbook” and the “Soul Sensation Cookbook.” These resources were intended to acknowledge the participants’ dietary preferences, and to educate them on how to enjoy these traditional foods in a healthful way. Diabetes self-management measures, which included showed initial improvement among the intervention group, however the improvements diminished by 24 months (Melkus et al.).

Tang et al. (2005) developed the “Lifelong Diabetes Self-Management Intervention” (LMI) for African American adults to address the reported lack of sustainability of diabetes self-management intervention achievements beyond six months post-intervention. The researchers noted that the culturally tailoring of this two-year intervention was grounded in its patient-centered, problem-focused approach, and in its being offered in the communities within which the participants lived. The LMI entailed a total of 88 weekly sessions held over the course of 24 months. Participants received usual care throughout a one-year follow-up period with no intervention. Results at the one-year follow-up showed continued behavioral improvements in glycemic control and cholesterol levels (Tang et al., 2012). Unlike any other culturally-tailored intervention reviewed here, the LMI demonstrated lasting results. The research
Deep Contextual Factors Addressed by Deep Structural Dimension

Interventions. To culturally tailor diabetes self-management interventions, researchers have utilized Community Health Workers (CHWs) to address more deeply rooted barriers like patient/provider trust and the participants’ lack of motivation to engage in social systems. Also termed Community Diabetes Advisors (CDAs), Family Health Advocates (FHAs), Church Diabetes Advisors, and other names based on their roles, CHWs have a deep understanding of the social and physical environment within which AAOA participants live (Keyserling et al., 2000; Norris et al., 2006; Samuel-Hodge et al., 2009; Two Feathers et al., 2005). They are also able to help participants navigate the systems within their communities by sharing information about resources that are available that promote and help to maintain adequate diabetes self-management behaviors (Cummings et al., 2013; Shah, Kaselitz, & Heisler, 2013; Two Feathers et al., 2007).

An example of this can be seen in the landmark, Racial and Ethnic Approaches to Community Health Detroit Partnerships (REACH Detroit) study (Two Feathers et al., 2005). Two Feathers et al. (2005) described the disinvestment and outmigration that has taken place in Detroit over the last 50 years, which has played a significant role in the current barriers to healthy eating and physical activity that African American residents currently face. This includes the availability of employment opportunities and educational attainment, as well as the availability of grocery stores and recreational facilities.

This culturally-tailored intervention, which consisted of five, two-hour classes every four weeks in two community-based settings utilized FHAs to help navigate
participants through these deep structural issues. The classes provided an overview about diabetes, as well as content on increasing physical activity and intake of fruits and vegetable, and decreasing intake of fats and dietary sugar. The final class addressed maintaining these behaviors within the context of their communities. The FHAs contributed cultural knowledge in the development of the intervention, conducted baseline surveys in participants’ homes, and delivered the intervention to the participants. They contributed a cultural sensibility to the research team.

Deep structural dimensions were addressed through the integration of religion into the African American curriculum, the accessibility of the community-based classes (which were offered several times per day to accommodate participants’ schedules), and the applicability of the intervention to the context within which participants lived. Researchers noted that participants were satisfied with the intervention, in part, because it was applicable to their daily lives. Statistically significant improvements were found in dietary knowledge and behaviors, physical activity knowledge, and HbA1c levels. No changes were found in physical activity levels or diabetes-specific quality of life.

In the EMPOWER study, Cummings et al. (2013) noted the historical and ongoing mistrust of health care providers that African Americans have identified as a barrier to diabetes self-management and care. This mistrust has affected the ways in which African Americans engage/disengage in social systems, including the health care system and health-related resources. Researchers noted that other barriers for this study’s sample included the under-resourced community within which the participants...
lived, namely the low income and high unemployment rates, and the limitations on physical activity and dietary options in their communities.

The EMPOWER study utilized six CHWs to lead the culturally-tailored intervention that was delivered individually to the 100 rural, low-income African American women (mean age 52 years) in the intervention group. Three CHWs provided behavioral coaching, and three CHWs assisted participants with finding community resources to facilitate and support effective diabetes self-management. Participants in the intervention group had 16 contacts with CHWs over the course of 12 months. The intervention focused on developing trust and capitalized on the social networks and cultural values that the participants and their CHW shared during the initial contact. The remaining contacts focused on diabetes self-management content, which included perceptions of diabetes self-management norms and expectations in addition to standard diabetes self-management education.

This prospective randomized trial was hypothesized to not only demonstrate improvement in HbA1c levels among the study’s participants, but to improve psychosocial factors that facilitate long-term diabetes self-management success. The researchers attributed this expected outcome to the use of culturally-concordant CHWs who received 50 hours of training for the intervention, and who were knowledgeable about navigating the participants’ social environment. The CHWs were able to help participants in dealing with barriers to medical and pharmacy care, as well as in finding community resources where they could gain access to healthy food and spaces for physical activity.
Agurs-Collins, Kumanika, Ten Have, and Adams-Campbell (1997) noted the vast availability of high-fat and high-salt foods in markets located in communities comprised of primarily African American residents. The researchers also described the deep structural implications of cultural beliefs that compete with standard diabetes treatment recommendations. These include deeply embedded cultural beliefs about physical activity, health, high-fat and high-salt foods, and the widespread lack of motivation to lose weight due to the commonness of obesity among African Americans. Despite these deeply embedded factors, the researchers aimed to improve diabetes self-management behaviors among AAOA women utilizing surface factors. Indeed, the intervention was evidence-based. These surface factors included culturally tailoring the intervention by depicting African Americans, as well as community settings, language, foods, social values and situations in ways that were meaningful to older, African American women. Results at three months indicated a significant net difference in mean HbA1c, weight, physical activity, and dietary intake of saturated fat and cholesterol between the experimental and control groups. Results for HbA1c and weight remained statistically significant at six months.

Discussion

Culture strongly influences diabetes self-management behaviors (Collins-McNeal et al., 2012; Leeman et al., 2008). Culturally tailoring diabetes self-management interventions is “the process of creating culturally sensitive interventions, often involving the adaptation of existing materials and programs for a racial/ethnic subpopulation” (Resnicow et al., 1999, p. 11).
Existing literature on culturally-tailored interventions for AAOAs with T2DM is scarce. In reviewing the literature according to surface and deep structural factors, it is worthwhile to note the different contexts within which cultural tailoring has been developed. Surface structural contexts have included socio-cultural mismatches in diabetes self-management programs and interventions (Keyserling et al., 2000); and, a reliance on churches as intervention settings due the familiarity and comfortability that African Americans have traditionally felt there (Collins-McNeil, 2012; Samuel-Hodge et al., 2009). Deep structural contexts have included disinvestment and outmigration patterns (Two Feathers et al., 2005); African Americans’ long-standing mistrust of health care providers (Cummings et al., 2013); rural environments as facilitators of obesity and inhibitors of weight loss (Anderson-Lofton et al., 2012); and, the abundance of high-fat and high-salt foods and eating establishments in African American communities (Agurs-Collins et al., 1997).

The widespread use of CHWs is also important to note. Engaging community members to intervene in helping to improve the self-management behaviors of African Americans has been grounded in the idea that the shared experiences and backgrounds of the community members aid in minimizing participant attrition, fostering a sense of support, and providing a link between the participants and resources available in their communities (Keyserling et al., 2000; Norris et al., 2006; Shah et al., 2013; Two Feathers et al., 2007). Although they do not typically intervene on a deep structural level, CHWs have opened a pathway for African Americans to engage in social systems that, at least temporarily, have improved their health behaviors.
In terms of the lasting effects of culturally-tailored interventions, researchers have noted that studies overwhelmingly show success/promise at one month, six weeks, three months and six months into or post-intervention (Norris et al., 2006). However, as noted by Tang, Funnell, and Oh (2012), the culturally-tailored diabetes self-management interventions consistently fail to demonstrate long-term improvement. Researchers have attributed the lack of long-term success to such factors as short intervention duration, lack of long-term follow-up, and the psychosocial impact of competing demands, life stressors, aging-related factors and lifelong experiences with economic and social disadvantage (Cummings et al., 2013; Melkus et al., 2010; Norris et al., 2006; Sumlin & Garcia, 2012). Research that has attended to deep structural interventions that address deeply embedded social and behavioral factors over longer study periods is scarce.

**Structural Racism, Health, and the Life Course**

The context within which today’s cohort of African American older adults (AAOAs) were born includes living within a few generations from slavery; being proximally situated during the Jim Crow era and mass migration period; enduring redlining practices and mass incarcerations; and, facing barriers to housing, employment, quality schools, health care, goods and services (Bonilla-Silva, 1994; Jones, 2000; Massey & Denton, 1993; Williams, 1997). This context has been shaped by structural racism.

**Structural Racism Defined**

Structural racism, also described as institutionalized racism, refers to the contour of a system that shapes and perpetuates racial ideology (Bonilla-Silva, 1994; Jones,
Racial ideology provides the basis for social, political, and economic interactions between races (Bonilla-Silva, 1994). These interactions are systemically reinforced through the continual process of producing racialized outcomes among multiple institutions (Powell, 2007). For instance, the interactions between public policies, institutional practices, cultural representations, and other norms reinforce one another, and perpetuate racial group inequity (Lawrence, Sutton, Kubisch, Susi, & Fulbright-Anderson, 2004). Racialized outcomes are marked by differential access to the goods, services and opportunities of society by race (Jones, 2000).

According to The Aspen Institute (Lawrence et al., 2004), many opportunities in the U.S. are shaped by race and racial ideologies. Gilmore (2007) stated that structural “racism is the state-sanctioned and/or extralegal production exploitation of group differentiated vulnerability to premature death” (p. 247). Bonilla-Silva (1994) called this concept “life chances”, and stated that a racialized society is distinguished by the differences in life chances between its racial groups. “Racialized social systems are societies that allocate differential economic, political, social, and even psychological rewards to groups along racial lines; lines that are socially constructed...[and] partially organize and limit actors’ life chances” for non-dominant groups (Bonilla-Silva, 1994, p. 472; p. 474).

According to Bonilla-Silva (1994), all racial social systems are hierarchical. The race placed in the superior position tends to receive greater economic remuneration and access to better occupations and/or prospects in the labor market, occupies a primary position in the political system, is granted higher social estimation (e.g., is viewed ‘smarter’ or ‘better looking’), often has the
license to draw a physical (segregation) as well as social (racial etiquette) boundaries between itself and other races, and receives what DuBois [1939] calls a ‘psychological wage’. The totality of these racialized social relations and practices constitutes the racial structure of a society (Bonilla-Silva, 1994, pp. 469-470).

In all of U.S. history, as a race, African Americans have never been situated in (or near) this superior position. This study’s participants were no exception having been directly affected by the Jim Crow era in the U.S.

**Jim Crow (1877-mid-1960s)**

There is a long history of legal protection for White advantage (Harris). Jim Crow laws, which were named after a popular minstrel song from the 1820s, were laws and etiquette norms that operated primarily in the southern U.S. and border states from 1877-the mid-1960s. Also known as the Black Codes, the government-sanctioned, caste system of racial oppression and segregation oppressed Black people in every area of daily life (Litwack, 1998; Pilgrim, 2012). Woodward (1955) noted that this code lent the sanction of law to a racial astracism that extended to churches and schools, to housing and jobs, to eating and drinking. Whether by law or by custom, that ostracism eventually extended to virtually all forms of public transportation, to sports and recreations, to hospitals, orphanages, prisons, and asylums, and ultimately to funeral homes, morgues, and cemeteries (p. 8). Religious leaders, theologians, scientists (craniologists, eugenicists, phrenologists, and social Darwinists), politicians, newspapers and magazines supported Jim Crow based
on the position that Blacks were innately inferior to Whites intellectually, morally, and culturally (Pilgrim, 2012; Smedley et al., 2002; Tischauswer, 2012).

Despite the passage of the 14th and 15th Amendments to the U.S. Constitution, which expanded civil rights and voting rights protections to all Americans, respectively, (Library of Congress, 2015a, 2015b), states passed their own statutes that regulated the social interactions between races—even to the point of including treatment at the time of death and disability. In Georgia, for example, the statute stated “The officer in charge shall not bury, or allow to be buried, any colored persons upon ground set apart or used for white persons” (National Park Service, n.d., Jim Crow Laws). In Louisiana, “The board of trustees shall…maintain a separate building…on separate ground for the admission, care, instruction, and support of all blind persons of the colored or black race” (National Park Service, Jim Crow Laws). Racial interactions in education, child custody, and the military, where not exempt. In Oklahoma, “Any instructor who shall teach in any school, college, or institution where members of the white and colored race are received and enrolled as pupils for instruction shall be guilty of a misdemeanor, and upon conviction thereof, shall be fined…” (National Park Service, Jim Crow Laws). In South Carolina,

It shall be unlawful for any parent, relative, or other white person in this State, having the control or custody of a white child, by right of guardianship, natural or acquired, or otherwise, to dispose of, give or surrender such white child permanently into the custody, control, maintenance, or support, of a negro (National Park Service, Jim Crow Laws).
In North Carolina,

The white and colored militia shall be separately enrolled, and shall never be compelled to serve in the same organization. No organization of colored troops shall be permitted where white troops are available and where whites are permitted to be organized, colored troops shall be under the command of white officers (National Park Service, n.d., Jim Crow Laws).

Jim Crow ideologies and practices also extended to limiting the voting rights and nursing care of Blacks. Voting limitations were imposed through grandfather clauses, poll taxes, white primaries, and literacy tests. Grandfather clauses included laws that restricted the right to vote to those people whose ancestors voted before the Civil War. Poll taxes were fees charged to poor Blacks who wanted to vote. Only Democrats could vote in primaries; only Whites could be Democrats. Literacy tests required Blacks to “Name all the Vice Presidents and Supreme Court Justices throughout America’s history” (National Park Service, n.d., Jim Crow Laws). The following law in Alabama reflected the discriminate nursing care against Blacks during this time: “No person or corporation shall require a white female nurse to nurse in wards or rooms in hospitals, either public or private, in which negro men are placed” (National Park Service, Jim Crow Laws). Jim Crow laws relegated African Americans to second class citizenship, and provided the institutionalized justification for anti-Black racism (Pilgrim, 2012; Tischauser, 2012).

**Hill-Burton Act (1946-1966)**

Burns Bolton, Giger, and Georges (2004) noted that the receipt of health care services was impacted by Jim Crow laws in the U.S. South, and by the Hill-Burton Act in
the northern regions of the U.S. Hill-Burton Act funds were hospital construction funds that were allocated to states in order to improve hospitals and eliminate disparities that existed between states regarding hospital resources (Almgren, 2013). Part of the provisions of the Act included anti-discrimination mandates and requirements that hospitals provide a reasonable amount of services for individuals who were unable to pay for care (Almgren). These provisions were left unenforced. In fact, the Hill-Burton Act allowed facilities that received federal funding to refuse admission to African Americans if “separate but equal” facilities were available nearby (Almgren). Former Editor of the American Journal of Public Health, George Rosen (1962) stated that the Hill-Burton Act was “perhaps the greatest existing obstacle to the fulfillment of” the American Public Health Association’s resolve to integrate health facilities and staffing (p. 1749). According to Almgren, the most significant historical criticism of the Hill-Burton Act is that it greatly slowed racial integration in the hospital industry. African Americans continued receiving disparate care with fewer or inadequate health resources within their communities.

**Redlining (1934-1968)**

Redlining is the systematic practice of excluding and denying primarily African Americans from such services as banking, insurance, and housing, as well as the inflation of costs for goods within majorly Black neighborhoods (Massey & Denton, 1993). Its roots are grounded in the federal government’s efforts to revitalize life for Americans in the 1930s. Katznelson (2005) noted that a full generation of governmental policies advanced Whites into homeownership and into suburban communities, while denying those opportunities for Black Americans. For instance, the federal government
started a series of programs aimed at increasing employment and the availability of homeownership, and the first of these programs was the Home Owners’ Loan Corporation (HOLC) (Massey & Denton).

The HOLC developed a ratings system that evaluated risks associated with loans offered to specific urban neighborhoods (Massey & Denton, 1993). Out of the four color-coded quality ratings, red was the lowest color-coded category and received nearly no HOLC loans. Red color-coded neighborhoods were those communities comprised of primarily Blacks, and also included areas that might contain Blacks in the future. This discriminatory model of undervaluing “red” neighborhoods and analyzing real estate worth based on the density and potential settlement of African Americans laid the foundation for both public and private credit institutions in the subsequent decades. The HOLC’s disinvestment in areas comprised of primarily Black residents influenced the underwriting practices of the Federal Housing Administration (FHA) and Veterans Administration (VA) in the 1940s and 1950s—the two loan programs that significantly fostered rapid suburbanization of the U.S. after 1945 (Massey & Denton).

Although the actual funds provided through their housing program were modest, the HOLC institutionalized the systematic practice of redlining and the further disadvantagement of Blacks in other aspects of life. Due to the strong linkage between a person’s residence and their access to resources (e.g., schools, business districts, jobs, transportation, medical facilities and interactions with the criminal justice system), housing discrimination constrains an individual’s higher education opportunities, labor market options, and health (Powell, 2007). Powell stated:
It follows that in order to fully understand why so many elderly African Americans and Hispanics live at or below the poverty line, we not only must retrace their lifelong relationship to the labor market, but also their relationship to the housing market and to the educational and criminal justice systems (p. 796-797).

**Racial Terror (1878-1977)**

Structural racism manifests itself in the form of acts of commission and acts of omission—i.e., intentionally strategizing to limit the opportunities and benefits of racial groups, and intentionally disinvesting or remaining inactive in the face of need (Jones, 2002). Many of the race riots that occurred from 1878-1977 were ignited by the latter, and occurred in both major cities and rural communities throughout each region of the U.S.

Until the 1950s, race riots co-occurred with lynchings (public hanging, shooting, burning, dismemberment, castration, and other physically torturous acts) of suspected criminals which were carried out by mobs (Gibson, 1979). Lynching was a community affair. As a result, lynchers were rarely indicted or sentenced because “the judges, prosecutor, jurors and witnesses (all white) were usually in sympathy of the lynchers. If sentenced, the participants in the lynch mobs were usually pardoned” (Gibson, Lynching). Additionally, police officers often participated in or permitted mob lynchings (Cutler, 1905; Gibson). The impunity of lynching is a demonstration of the acts of omission that occurred on a structural level.

The increasing pattern of violence by White mobs against Black communities was described by Nobel Laureate Gunnar Myrdal as mass lynching (Gibson, 1979). More commonly referred to as race riots, these community-based attacks were rooted in
efforts to disenfranchise, disempower, and suppress Blacks politically, socially and in the labor market. Gibson noted that the large-scale interracial violence became almost epidemic as Blacks increasingly migrated from the South to the North.

James Weldon Johnson described the summer of 1919 as “Red Summer” in reference to the race riots that occurred in more than 35 U.S. cities between summer and autumn of that year. By 1919, approximately one half million African Americans emigrated from the South to the North to escape lynchings and Jim Crow laws. Many also emigrated to industrial northern and midwestern cities to secure work. Racial tensions escalated as Black workers were hired as strike breakers and as workers in jobs that were traditionally held by Whites.

Race riots were a systemic issue. Structural racism was demonstrated by the inaction of the system to protect and serve all communities. Common among each race riot that occurred within this time period, was the overwhelming massacres of Blacks, as well as attacks on and burning of Blacks’ homes and businesses. These assaults left thousands of African American families homeless or displaced. The violence also left many families with family members who had been severely beaten or killed (Gibson, 1979). Police departments and courts rarely responded to or acted on these inhumane and illegal acts of violence. In fact, when Black people attempted to resist assaults by mobs of Whites, the police would arrest them for arming themselves in self-defense (Gibson). Boskin (1976) noted that

The police force, more than any other institution, was invariably involved as a precipitating cause or factor in the riots. In almost every one of the riots, the
police sided with the attackers, either by participating in, or failing to quell the attack (p. 14).

**Relationship to Health**

Structural racism is a developing concept within the health disparities literature. In the nursing literature, Burnes Bolton, Giger, and Georges (2004) contended that structural racism is an intervening variable that either hinders access to health care or perpetuates culturally inappropriate care. Giger and Davidhizar (1999) suggested that structural racism is an explanatory factor for the high rates of morbidity and mortality among racial and ethnic minorities. African American older adults have particularly borne the brunt of the racial restrictions imposed on them throughout their lives. As such, researchers contend that structural racism provides a causal explanation for why AAOAs are increasingly experiencing worse health outcomes than most other racial/ethnic groups (Smedley et al., 2002).

Gee and Ford (2011) noted that individuals who self-report experiences of interpersonal racism have greater rates of morbidities. On a population level, the authors contended, the health of social groups is affected by structural forms of racism. This line of thinking is complimented by *Healthy People 2020* goals which identify discrimination and residential segregation as examples of social determinants of health. These and other macro-level forces (systems, institutions, and ideologies) continually interact with one another to perpetuate conditions that lead to negative health outcomes (Bonilla-Silva, 1994; Gee & Ford; Jones, 2002; Powell, 2007; Williams, 1997).
Social segregation within communities, schools, workplaces and health care facilities is one dimension of structural racism that is associated with the health of racial groups. For example, Powell (2007) noted that

Residents of poor, segregated neighborhoods experience poorer health outcomes because of increased exposure to the toxic substances that are disproportionately present in their communities, and because of greater barriers to sustaining healthy behaviors, such as limited access to adequate grocery stores (p. 806).

Evidence also shows that racial/ethnic minority workers are more often in jobs with fewer benefits, greater exposure to environmental hazards, and with more stressors—all of which are associated with a variety of health conditions (Gee & Ford, 2011).

**Health Behaviors.** In terms of the impact of social experiences on health behaviors, segregation within schools (i.e., advanced vs. less advanced courses) has been associated with health behaviors such as alcohol use among students (Walsemann & Bell, 2010). Thomas and Thomas (1999) found that social structures that shaped a rural region in North Carolina affected sexual behaviors that facilitated sexually transmitted disease transmission. Kwate et al. (2003) found that the number of cigarettes and alcoholic drinks consumed by African American women was positively correlated with racism experienced in the past year. Smith and Ruston (2013) found that the broader structural and institutional context surrounding a marginalized ethnic group in the United Kingdom (including ethnic segregation and social discrimination) affected their health care utilization. This finding was particularly significant because the
sample’s reported exposure to racism and prejudice was associated with anxiety and stress-related disorders and increased intake and reliance on alcohol and drugs.

Negative coping behaviors such as smoking, alcohol and drug abuse, and risky sexual behaviors arise among those who report experiences of interpersonal and institutionalized racism (Kwate et al., 2003; Thomas & Thomas, 1999; Walsemann & Bell, 2010). However, these negative behaviors run in tandem with the positive coping behaviors of others who report similar experiences. Of particular note are the positive coping behaviors termed *John Henryism* (Williams and Mohammad, 2009) and *Sojourner Syndrome* (Lekan, 2009). These psychological and emotional coping strategies have been explained as being useful to African Americans in dealing with difficult environmental and psychosocial stressors, health problems, and racism, and in adapting to oppressive social circumstances over a prolonged period of time (James, 2011; Lekan, 2009). However, John Henryism and the Sojourner Syndrome have also been associated with higher rates of cardiovascular disease, breast cancer, osteoarthritis, sickle cell disease, and death among African Americans (Duke Medicine News, 2006; James, 2011; Lekan, 2009; Williams & Mohammad). Like smoking, drinking alcohol, abusing drugs and engaging in risky sexual behaviors, the health effects of high effort coping with psychosocial stressors occur over many years (James).

**Cumulative Effects.** The cumulative effects of stress have been described in the literature using such terms as *weathering* and *allostatic load*. These terms refer to the cumulative impact of the chronic stresses associated with living in a social world that was intentionally constructed to disadvantage African Americans in most facets of everyday life (Geronimus et al., 2006; U.S.DHHS, 2010). Geronimus et al. found that
the constant threat of inhumane treatment, social injustice, and systematically imposed barriers in a racially-charged atmosphere may show its greatest effects on African Americans. Using NHANES data, Geronimus et al. suggested that this stress may cause disproportionate physiological deterioration, and result in morbidity and mortality rates typical of White persons whom are older.

Gee and Ford (2011, p. 125) described Darity’s (2003) hypothesis of intergeneration drag, which posits “Ethnic or racial groups pass social assets and liabilities on to their descendents”. This perspective extends the idea of cumulative effects of structural racism experienced throughout AAOAs’ individual life courses to the cumulative effects of structural racism-related experiences of African Americans throughout generations. Today’s cohort of AAOAs carry with them the experiences of their parents and grandparents, who were socially devalued and structurally disadvantaged, along with their own lifelong, personal experiences with systematic barriers.

Conclusion

Researchers have laid the groundwork for this study by presenting the implications of structural racism on the health and coping behaviors of African Americans. From a social determinants of health perspective (i.e., from a framework of examining the social context within which AAOAs were born, have lived, worked and aged), researchers have noted the health consequences that occurred as a result of Jim Crow laws, the Hill-Burton Act, redlining and race riots. As a result of their work, we know that social conditions affect health, health access, and have led to negative health consequences for AAOAs. From a life course perspective, researchers have explained
that early life social experiences inform later life health behaviors. Consequently, we understand that the continuum of social experiences and systemic interactions over time impact how AAOAs engage in daily coping behaviors (smoking, drinking, abusing drugs, adapting, or working excessively). Finally, we know that living within a racialized society limits the life chances, including the health-related chances, of non-dominant groups (Bonilla-Silva, 1997). Although growing attention is being directed toward the structural factors that might continue to negatively affect the life chances of AAOAs, the impact of a lifetime of structural racism-related factors on the health behaviors of AAOAs remain understudied.

This study was designed to uncover the impact of structural racism on inadequate diabetes self-management behaviors among AAOAs. Although T2DM is a manageable condition that can increase the life chances of those with the condition, what we have yet to understand is the impact that a lifetime of social disadvantage as a result of structural racism-related factors has on the ways in which AAOAs with T2DM inadequately take care of themselves and their condition.
STUDY DESIGN AND METHODOLOGY

The researcher used a qualitative approach to develop the resulting grounded theory. Classic grounded theory provides a systematic means for data collection, analysis, and for the generation of theories that are grounded in the data themselves (Creswell, 2007; Lincoln & Guba, 1985). Constructivist grounded theory extends classic grounded theory by recognizing that data collection and analysis are influenced by the views and interpretations that researchers draw from their past and present interactions with people within the research setting, and prior conceptualizations that have sensitized their ideas (Charmaz, 2006). In fact, not only are the data collection and analysis processes influenced by the researcher, a constructivist approach acknowledges the researcher’s role in co-constructing the data. As such, the resulting theory is based on the researcher’s interpretation of the data in tandem with the researcher’s shared experiences and relationships with the research participants, and the underlying conceptualization that stimulated the research questions.

Charmaz (2006) noted that constructivist grounded theory utilizes an interpretive approach, which emphasizes understanding a phenomenon as opposed to simply explaining it. The researcher gains understanding by establishing a rapport with participants, entering the participants’ worlds, and seeking to understand those worlds from the participants’ points of view. Understanding is also derived from observing participants’ behavior and through participants’ narratives.

Constructivist grounded theory methodology was a useful tool in guiding my investigation into the relationships between AAOAs’ lifelong experiences with structural
racism and diabetes-related experiences in older age because there is a dearth of literature that has aimed to understand the known and taken-for-granted experiences that African American seniors have had with racism on a structural level—particularly among those seniors with uncontrolled diabetes. A constructivist grounded theory methodology helped me to collect background knowledge, detailed descriptions about participants’ experiences, uncover patterns of thinking and behavior that were layered beneath the surface of their ascriptions, and to gain multiple views that helped to shape analytic categories.

Sampling

Initial Sampling

During the initial phase of sampling, participants were sought using the inclusion criteria outlined in the study proposal. To be eligible for the study, women and men needed to be aged 55 years and older, self-identify as “Black” or “African American”, and have a medical diagnosis of diabetes with an HbA1c of 8.0% or higher at the time of recruitment. Additionally, participants needed to be community-dwelling and able to care for themselves independently. Potential participants who self-reported a terminal illness, had cognitive impairment, had an HbA1c of 7.9% or lower, or were unable to care for themselves independently were ineligible for participation. As the Principal Investigator, I determined eligibility at the time of screening based on results from an Eligibility Determination Form (Appendix 2), and based on the participants’ understanding of the study.

During initial sampling, the semi-structured questions that I asked participants in focus groups and individual interviews pertained to the research questions. I wanted to
know what types of structural racism-related experiences participants endured throughout their lives, what they remembered about how they felt and thought when experiencing those events, and what their experiences have been living with diabetes. These initial interviews produced data that I saw “clumping” together according to a variety of codes. Codes are labels that describe segments of data and indicate what the segments are about (Charmaz, 2006).

As I wrote memos about these codes, I identified additional questions that I wanted to ask in subsequent interviews. I wanted to understand the thoughts and feelings that participants were describing within the context of actual stories. For example, a frequent code that I identified throughout the first series of interviews was “taking care”—taking care of one’s self, taking care of one’s social networks, and being taken care of by others. Writing memos about these forms of “taking care” informed the questions that I asked in subsequent interviews.

**Theoretical Sampling**

The process of using focused codes to direct future interviews (theoretical sampling) allows the researcher to explore codes more deeply, to organize and refine the codes into categories, and to identify properties and dimensions of categories that develop into theoretical concepts (Charmaz, 2006; Corbin & Strauss, 2008; Glaser & Strauss, 2011). For instance, I was able to ask more directed questions about the phenomenon of “taking care” in subsequent interviews when I identified it as a frequent focused code across interviews. These questions sought a more detailed description of the context that shaped the need or desire for “taking care” to occur. I aimed to understand what motivated participants to “take care” of themselves or others, or to
allow or refrain from allowing others to “take care of” them in the experiences that they described. I also focused on how “taking care” was enacted, and what meanings “taking care” had for participants.

Theoretical sampling was a tool that enabled me to identify patterns that I recognized across interviews. These patterns eventually led to themes and the theoretical concepts of my grounded theory. This process enabled me to reach theoretical saturation, the goal of grounded theorists in grounded theory generation (Charmaz, 2006).

Research Setting

This study was carried out at senior sites operated by a community-based, human social services organization in South Los Angeles. This non-profit organization served primarily racial/ethnic minority older adults as part of its multi-focal, social service initiatives. At the request of the Director of Senior Services, I travelled to several of the organization’s senior center and housing sites to recruit and collect data, as opposed to having the seniors bussed to one central location during data collection.

The senior sites were all located in Los Angeles Service Planning Area (SPA) 6, which served the communities of Athens, Compton, Crenshaw, Florence, Hyde Park, Lynwood, Paramount and Watts. SPA 6 contained the largest percentage of African Americans, and among the highest rates of diabetes and diabetes-related complications in Los Angeles County (Los Angeles County Department of Public Health, 2009). I volunteered with the non-profit organization at its senior sites for several months before this study was developed. As such, I had an established rapport with both the staff and several clients at the time of this study.
Recruitment

I used an UCLA Institutional Review Board (IRB)-approved recruitment flyer (Appendix 3) to invite potential participants to learn about this study. Staff from the organization posted copies of the flyer, and handed them to African American seniors whom the staff knew had diabetes. I distributed flyers to seniors who were enrolled in the organization’s diabetes self-management classes, at the organization’s diabetes awareness fair, and at an insurance enrollment fair that was sponsored by the organization. I also distributed the recruitment flyer to seniors with whom I had established a rapport during my previous volunteer work with the organization.

Recruitment Barriers

Despite my prior work and established rapport with seniors within the organization, I faced unexpected recruitment challenges after my first focus group and round of subsequent individual interviews. I was asked to participate in the organization’s diabetes fair where I expected to garner a lot of interest from the self-selected group of seniors who were in attendance. After completing a well-received talk about diabetes and its complications, I let the seniors know about my study. The response to sign up for the informational meeting was minimal; I did not anticipate such low interest. I wondered if making the announcement to a large room of people was stigmatizing in some way for individuals with diabetes. I wondered if the seniors simply did not want to be in my study. I wondered if they did not trust me as much as I thought that they did.

After the event, I spoke with a staff member about my concerns. The staff member suggested that I offer free giveaways next time to people who followed-through
with the eligibility determination process. That seemed coercive to me, and not an option that I wanted to pursue. Two staff members offered to contact their clients directly to let them know about my study. I sent a follow-up email thanking them for their offer to help facilitate recruitment.

One of the staff members posted the recruitment flyer on her office door with a sign-up sheet for my scheduled information session next to it. Six seniors signed up to attend. When I arrived on the scheduled day, all six seniors were present. However, as I began giving information about the study, I discovered that none had diabetes. This group was made up of seniors who wanted to learn more about diabetes, or who wanted to help a family member to manage their diabetes better. In response to the confusion, the two staff members came up with a plan to distribute flyers directly to seniors who they knew had diabetes.

After the two staff members articulated their plan, I sent them a follow-up email that thanked them for their offer to help with my recruitment efforts again. I was confident that I would have a better success than the prior experience. Within a couple of days of our conversation, one of the staff members asked that I email the flyer to her so that she could make additional copies. When I spoke to the other staff member, she said that she would start talking to people the following week, as she “didn’t feel like doing it” on the days prior. That was a surprising response; this staff member came up with the idea for the two staff members to approach seniors personally.

By the end of the following week, I was told there were 15 seniors with diabetes who were interested in attending an informational meeting. We scheduled a time that worked for the center. A couple of days before our scheduled meeting, I received an
email that stated that both staff members decided that they needed to push back the informational meeting. Apparently, one staff member did not contact the people she committed to reach; and, the other staff member realized that the people who she confirmed did not have diabetes, or were no longer interested. This was perplexing.

I conferred with a seasoned researcher who has worked with this organization on several research projects. The researcher suggested that I handle everything that I possibly could on my own, so as to not burden the staff and to keep my project moving forward. This advice improved my recruitment efforts greatly. I took responsibility for distributing flyers and following-up with interested seniors, and only contacted the staff to keep them abreast of my progress and to request times to meet seniors in their sites.

**Screening, Enrollment and Study Sequence**

**Visit One**

The study sequence is outlined in Figure 1. The study was carried out over the course of three “visits”. Visit One was my initial meeting with potential participants where I explained the study; what I was asking the participants to do; what the screening process would entail; and, what the incentive would be for their participation (Appendix 4). Individuals who wished to proceed stayed in the room and engaged in the screening process.

**Screening.** The screening process began with participants filling out an Eligibility Determination Form. Help was offered to anyone who wanted assistance completing this form. Potential participants were also given the option to refuse to answer any question that they were uncomfortable with, or did not want to answer. I met with each potential participant one-on-one to review their answers and to confirm their
understanding of the study. If all of the inclusion criteria were met, I collected a blood sample to determine if their HbA1c was above 7.9%.

**HbA1c Testing.** HbA1c levels indicate individuals’ average glucose control during the previous two to three months. It reflects the percentage of the hemoglobin that is glycated—or, irreversibly bound by glucose. HbA1c is associated with adequate/inadequate self-management behaviors (Walker et al., 2013).

The HbA1c level enabled me to determine if the participant met the study’s “uncontrolled” inclusion criteria. Participants whose HbA1c level was $> 8.0\%$ were eligible. Although 7.0% is generally considered the target goal in healthy adults with good functional status, evidence supports the use of a less stringent A1c target of 8.0% in select older adults (California Healthcare Foundation/American Geriatrics Society Panel on Improving Care for Elders with Diabetes, 2003; Inzucchi et al., 2012).

I used *PTS Diagnostic’s A1C Now+*, the industry standard for obtaining rapid A1c results. I followed the testing procedures as outlined by PTS Diagnostic (PTS Diagnostic, n.d.). To perform the test, I administered a finger stick to obtain a small, 5 μL blood sample. I added the blood into the device’s shaker, shook the blood sample six to eight times, inserted the cartridge into the monitor, delivered the blood sample from the shaker into the cartridge, and waited approximately 5 minutes until the sample had been processed. If the potential participant’s HbA1c level met the study’s eligibility criteria, they were given the option to enroll in the study.

**Consent and Enrollment.** I reviewed the UCLA IRB-approved consent form with each person who chose to enroll in the study. Upon completion, the participant was given a Demographic Data Form (Appendix 5), and I obtained the participants’ contact
information in order to remind them of their scheduled visit two and visit three appointments.

**Incentive**

Participants received a gift bag of diabetes products and education materials. I obtained coupons from Abbott, the company that manufactures Glucerna products, to purchase items to include in the gift bags. Also in the bag were printed materials about diabetes and how to self-manage the condition.
Data Collection

My aim during data collection was to capture the words, emotions, thoughts, intentions, and motivations of my participants within the frame of the social environment that surrounded and structured their lives. To obtain depth in the data, I interviewed my participants twice—in a focus group, and in an individual interview.

The intent of each interview differed. I used focus groups as an opportunity to talk about structural racism-related experiences that occurred throughout participants’ lives. Because I was relying heavily on participants’ recall of past events and the thoughts and feelings that they remembered experiencing when the events occurred,
my hope was that the dialogue among participants would trigger details about events that they may not have otherwise remembered. I was primarily interested in participants’ diabetes-related experiences during their individual interviews. However, there were a few occasions when I used the beginning of the interview to clarify or obtain more understanding about structural racism-related experiences that participants shared in their respective focus groups. Meeting with participants in the focus group setting before interviewing them individually proved to be helpful in building rapport between each participant and me.

Finally, I gained insights by taking note of observations that I made in the research setting by writing field notes. I also wrote a copious number of memos as I transcribed, reviewed and reflected on the data. Finally, I read news articles and published reports that were related to participants’ structural racism-related ascriptions.

**Visit Two: Focus Groups**

Each focus group lasted 60 to 90 minutes, was recorded and transcribed and consisted of no more than five participants at a time. According to Morgan (1996), smaller groups give each participant time and opportunity to share their views and experiences. Smaller groups also allow the moderator to manage active discussions. I served as the moderator for each focus group.

Each focus group session began with introductions, and I explained the purpose of the study, how the participants were chosen, how the data would be handled, and provided an overview of the focus group process. I reviewed confidentiality, asking that participants not share what was discussed during the focus group; and, stated that
confidentiality could only be protected to the extent that participants did not share one another’s stories. Then, I answered participants’ questions before beginning.

I used semi-structured questions, and had printed photos of historical and contemporary events available to use if photo elicitation was needed to stimulate participants’ thoughts, feelings, memories, or discussion about historical events and the social context within which the participants had lived (Harper, 2002). Photo elicitation was not needed during the focus group discussions.

Visit Three: Individual Interviews

I used semi-structured interview questions to collect detailed accounts from participants. The goal of the individual interviews, which lasted 60 to 90 minutes, was to deepen the conversation from the focus group by exploring the individual experiences of participants. The one-on-one, tape-recorded interviews also provided an opportunity for participants to share personal information that they may have been reluctant to share in their respective focus groups.

Data Analysis

In keeping with grounded theory methodology, data collection and analysis occurred simultaneously (Corbin & Strauss, 2008). Interviews were transcribed verbatim, coded, and the codes were compared against one another in the form of memos and diagrams.

Coding

Initial Coding. After interviews were transcribed verbatim, I went line-by-line through each interview and named what was occurring in the data. This allowed me to break down the data into manageable pieces (Charmaz, 2006). My aim was to capture
and condense ascriptions and actions, using gerunds to describe what was going on from the participants’ points of view, and using in vivo codes to maintain the symbols and meanings described by participants (Charmaz, 2006; Saldana, 2009).

**Focused Coding.** Then, I moved on to focused coding, a second cycle of coding that allowed me to code incident-by-incident using more conceptual and abstract statements about what I saw occurring in the data (Charmaz, 2006). This process eventually allowed me to identify meanings that were embedded within participants’ words and actions as I utilized analytic techniques such as memoing, constant comparison, and mapping.

**Memoing**

While going through initial and focused coding, I wrote memos to help clarify my ideas and explore hunches about what the codes might mean, and how the codes may have been related within and across interviews. I also wrote memos to examine the judgments and biases that I might have been imposing upon the data and the data collection and analysis processes (Charmaz, 2006).

**Constant Comparison**

Because data collection and analysis co-occur when constructing a grounded theory, the data are constantly being compared against one another. Glaser and Strauss (1967) noted that this process can lead to a “developmental” theory (p. 114). As I saw similarities between focused codes grouping together into categories, and as new focused codes and categories developed throughout the data collection and analysis processes, I compared the old and new codes to each other to see if they fit, expanded, or contradicted one another. This constant comparison process helped me to identify
properties and dimensions of categories by collapsing focused codes together, shifting 
other focused codes into different (and at times multiple) categories, and eliminating 
codes that no longer seemed significant in the developing theoretical “story”.

**Mapping**

Another analytic tool that was useful during data analysis was mapping. Clarke 
(2005) presented the technique of creating situational maps to explore relationships and 
interactions between elements that make up codes and categories. In keeping with the 
example described above related to “taking care”, I drew a messy map that identified 
people who were mentioned by participants (e.g., mother, stepfather, grandchildren, 
children, coach), institutions that were noted (e.g., job, military, school), emotions that 
were described in association with these elements (e.g., love, pain, pride, fear), and 
motivations that were related to the act of “taking care” (e.g., role requirement, to protect 
self or others, to prevent, to prepare for). Once words and phrases within each messy 
map were completed, I drew lines to connect related elements. Mapping helped me to 
clarify categories, and identify relationships within and between categories that I 
previously overlooked. As a point of clarification, my example above of using mapping 
as an analytic tool to identify relationships and interactions between elements 
understated the variety of anchor codes that were also included in the map.

**Trustworthiness**

Lincoln and Guba (1985) stated that the trustworthiness of a study establishes 
credibility (the “truth” of the researcher’s findings), transferability (application to other 
contexts), dependability (a consistent process that is able to be repeated), and
confirmability (findings that are as free from the researcher’s biases as possible). I utilized several evaluative techniques to establish trustworthiness in this study.

Credibility

Credibility is an evaluative criterion that helps the researcher maintain confidence in their data (Lincoln & Guba, 1985). I used triangulation—the use of multiple data sources—to help evaluate the “truth” of my findings. This was an important exercise to evaluate my interpretations of the meanings that I associated with participants’ structural racism-related ascriptions. I read contemporaneous news articles from the mainstream media; contemporaneous feature articles that were written by Blacks, for Blacks in Black-owned publications; and, contemporaneous reports that were published by local and federal government agencies.

Additionally, I wrote many memos throughout data collection and data analysis to clarify my ideas and interpretations of the data. I wrote memos that were reflections on my interviews, explorations of thematic hunches, concept analyses on frequent words or phrases that were used by participants, and thought-pieces related to the emerging theory.

Transferability

Lincoln and Guba (1985) noted that transferability for the naturalist (in contrast to the conventionalist who pursues external validity) can be achieved through thick description (i.e., providing detailed accounts of the observations, interactions, and experiences in the field and in the data). Although this study’s sample was small (N=15), I aimed to provide a description of the time and context of the events and experiences with the participants’ narratives. This exercise was grounded in Lincoln and Guba.
Dependability

Dependability is an evaluative tool to determine whether the research process was consistent and is able to be repeated (Lincoln & Guba, 1985). My process entailed gathering focus group data, followed by individual interview data, writing field notes and memos, and checking my interpretations against published accounts. I kept maintained a detailed review of the screening, data collection, analysis processes, which were available for routine audit (Lincoln & Guba).

Confirmability

My reflexive memos were used to address confirmability. For example, to explore a hunch, I would use other participants’ stories to determine if the attributes of the hunch held up across cases. Additionally, I met with a colleague regularly during my data analysis process to share interpretations of my findings and my developing theory. This audit process helped to assess if the inferences that I was drawing were logical. My colleague provided feedback that either supported my interpretations or challenged me to re-evaluate my data. These meetings helped me to remain as objective as possible in the interpretation of my findings, and to draw conclusions that were grounded in the words and experiences of my participants.

Human Subjects Protection

Privacy and Confidentiality

This study was approved by the UCLA IRB (Appendix 7). Participants’ privacy was maintained throughout each step of the screening and data collection process. I spoke with each participant individually during the screening process, and met with each participant individually during their one-on-one interviews. Participants were
encouraged not to use each other’s real names during focus groups even though many of the participants in each focus group were already well-acquainted with one another.

Confidentiality was maintained through the use of unique identification numbers that were linked to each participant. The coding key was stored in a locked filing cabinet to which only I had access. Audio recordings from the focus groups and individual interviews were destroyed after they were transcribed verbatim, and all transcripts were de-identified.

Risks to Participants

Whitbeck, Adams, Hoyt, and Chen (2004) found that there is an association between thinking about historical trauma and depression or anger. Due to this study’s focus on structural racism-related experiences that had occurred throughout the participants’ lives, there was a risk that participants might feel distressed as a result of talking about these events. I made participants aware of a printed list of resources that I had available should they need psychological support during or after our interviews. A licensed social worker, case manager, and mental health professional were accessible during the times of our interviews as well. No participants experienced distress or required psychological support following our interactions.

Methodological Challenges

Because racism may be over- or understated by AAOAs due to their heightened awareness of the experiences, or their having “moved past” or “survived” it, structural racism-related data collected within interviews may be constrained (Ford & Airhihenbuwa, 2010b). In my attempt to account for these challenges, I aimed to focus
on having my participants’ describe their experiences, as opposed to labeling those experiences as “racism”.

Also, given that AAOAs who live in Los Angeles have often migrated from various U.S. regions, data collected in focus groups reflected accounts that were, at times, regionally-specific. I accounted for regional differences during data analysis, and by asking regionally-specific questions during data collection.
Chapter 5

FINDINGS

The purpose of this constructivist grounded theory study was to understand the relationship between structural racism-related experiences in early life and diabetes-related experiences in older age among African American seniors with uncontrolled type 2 diabetes. The specific aims of the study were to: (1) describe structural racism-related experiences that AAOAs with uncontrolled T2DM had endured throughout their lives; (2) identify the personal meanings that AAOAs with uncontrolled T2DM ascribed to structural racism-related experiences; (3) identify meanings that AAOAs with uncontrolled T2DM ascribed to their diabetes and diabetes self-management; and (4) generate a theory that was grounded in the narratives of AAOAs with uncontrolled T2DM that deepens our understanding of the relationship between lifetime experiences with structural racism and uncontrolled diabetes in older age.

This chapter begins by providing an overview of the participants’ demographic characteristics. It progresses by revealing participants’ experiences with living in an environment that structurally oppressed and disadvantaged them, and ultimately provoked them to take control of themselves and their families over the course of their lives. The chapter then moves into describing participants’ experiences with diabetes and diabetes self-management—a condition which many of the participants were forced to accept, understand and learn to manage as they transitioned into older adulthood. This chapter concludes by proposing a connection between these two experiences—i.e., the experience of learning to survive within a social environment of limitation, and
learning to survive a health condition that threatens to impose limitation in their daily lives.

Sample

Demographic Characteristics

Women made up 53% of this study’s sample (8/15). The mean age of the sample was 65.5 years at the time of data collection. Approximately one-quarter of the sample was married. All of the participants had a high school-level education or higher, and two participants completed military service. Thirty-three percent (5/15) of participants declined to state their annual income. Among those who self-reported their income, most stated that they earned less than $30,000 per year (Table 3).

Table 3. Demographic Characteristics

<table>
<thead>
<tr>
<th>Demographic Characteristics (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>&lt; 65 years</td>
</tr>
<tr>
<td>65-75 years</td>
</tr>
<tr>
<td>&gt; 75 years</td>
</tr>
<tr>
<td>Marital Status</td>
</tr>
<tr>
<td>Never Married</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Separated/Divorced</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td>Highest Level of Education</td>
</tr>
<tr>
<td>High School/GED</td>
</tr>
<tr>
<td>Technical/Trade School</td>
</tr>
<tr>
<td>Some College</td>
</tr>
<tr>
<td>Associate’s Degree</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
</tr>
<tr>
<td>Military Service</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Annual Income</td>
</tr>
<tr>
<td>Less than $30,000</td>
</tr>
<tr>
<td>$30,000-$49,999</td>
</tr>
<tr>
<td>$50,000-$69,999</td>
</tr>
</tbody>
</table>
Declined to State 5 (33%)

U.S. Regions from which Participants Migrated to Los Angeles

<table>
<thead>
<tr>
<th>Region</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Born in Los Angeles Area</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>Northeast</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>South</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>West</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Outside of U.S.</td>
<td>1 (7%)</td>
</tr>
</tbody>
</table>

U.S. Regions of Origin

According to the U.S. Census Bureau (2015), there are four major regions of the U.S.: Region I (Northeast), Region II (Midwest), Region III (South), and Region IV (West). The “Deep South” is a term that Americans roughly associate with the lower south of the “cotton states” (Davis, Gardner & Gardner, 2009). This area stretches from the Atlantic Ocean to west of the Mississippi River, and typically refers to South Carolina, Georgia, Florida, Alabama, Mississippi and Louisiana, and is culturally distinguished from other states in the South based on its historical dependence on plantation-type agriculture before the American Civil War (New World Encyclopedia). According to Davis and colleagues, although the South was defeated in the Civil War, and ended the slave-master relationship between Blacks and Whites, respectively, the new social system that was established continued to rank Blacks as inferior and Whites as superior in all aspects of social life.

Forty percent (6/15) of participants were born in Los Angeles, and an equal number migrated from the South Region. Of those who migrated from the South, four participants came from the Deep South. One participant migrated to Los Angeles from a Caribbean country.

Table 4 identifies the developmental stage when migration to Los Angeles occurred for participants who were not born in the city. Two-thirds (10/15) of the
participants lived in Los Angeles by the time they were adolescents; 20% (3/10) migrated as they were developing during their young adult years; and, 13% (2/10) arrived to Los Angeles during middle adulthood.

Table 4. Developmental Stage When Migration to Los Angeles Occurred

<table>
<thead>
<tr>
<th>Developmental Stage</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Childhood (0-5 years)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>School Age (6-12 years)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Adolescence (13-19 years)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Young Adulthood (20-40 years)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Middle Adulthood (40-65 years)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Older Adulthood (65+ years)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

**Describing Structural Racism-Related Experiences**

The first aim of the study was to describe structural racism-related experiences that AAOAs with uncontrolled T2DM have endured throughout their lives. Four major categories were identified (Figure 2): (1) Being separate, (2) Facing threats, (3) Experiencing injustice, and (4) Protecting personhood. Additionally, two sub-categories of Being separate were found—Experiencing difference and Being under-resourced; as well as two sub-categories for Facing threats—Being warned to stay away and Dealing with intimidation.
Figure 2. Major and Sub-Categories of Structural Racism-Related Experiences

**Being Separate**

The category “Being separate” was defined in terms of Blacks being kept apart from Whites in residential and social settings. Participants described being separated from the White race by law. “I remember the Jim Crow law... It was a law that Blacks couldn’t live among the White community” (#1). They described being separate from Whites within shared facilities in their social environments. “Went to the dentist—White [waiting room on one side]; Black [on the other]. Restaurants—White; go around to the back—Black. Same building. Same cook. Same dentist” (#14). They also described being separate in terms of the establishments to which they had access. “I can remember...when I was a little girl...being downtown and my aunt would take me into certain stores. But, I would point out other stores that I saw and ask her, “Can’t we go in there?” She would whisper, “No. Colored people can’t go in that store” (#9). These
ascriptions were describing the social environments where participants lived in the West South Central division, Deep South area, and Mid-Atlantic division of the South, respectively.

**Experiencing Difference.** As a sub-category of “Being separate”, “Experiencing difference” highlighted the dissimilarity between the everyday experiences of Blacks and Whites. One dimension of “Experiencing difference” related to the variations in the physical characteristics that participants observed in shared social settings.

We’d go to the [movies] on the weekend …. Blacks would have to sit upstairs in the balcony with the wooden chairs… They wouldn’t let them sit down below. Occasionally, they would open up the gates for the Blacks to sit in the soft-cushioned chairs up in the balcony. (#1)

“Experiencing difference” also occurred when riding transportation. “I remember riding the Greyhound bus to visit my grandparents. Mom would automatically go straight to the back… We would say, ‘Mom, why we got to go way back here?’” (#14). Being separate and experiencing difference were part of everyday life.

The other dimension of “Experiencing Difference” was related to the imbalance of social power between Black and White Americans. Participant #13 recalled visiting family in the Deep South when he was an adolescent:

So [my brother, my two cousins and I] go [to the restaurant] and we start ordering the food, right. So, my two cousins go before me and my brother. And it’s a little White girl standing at the cash register. She couldn’t have been more than six or seven [years old]. And, we were like 10 and 11 [years old]… So, my two cousins go and order their food, and they tell the girl “Oh, we want a pineapple malt and a
hamburger.” And the girl said, “That’s what you want, boy?” And they go, “Yes, ma’am.” To a seven-year old girl, right? So, me and my brother looked at each other like, “What the--really? Why y’all call that little girl ‘ma’am’? That’s a little girl. She’s younger than y’all!”… They act like they didn’t even hear us. We couldn’t believe it. (#13)

Experiencing race-based power differentials was not surprising to Participant #15. This participant lived the first 16 years of his life in the Deep South before enlisting in the military.

Race was one of the top 5 things in the White people’s world. The fact that they had a say-so over a race of people that they could tell to do anything, or talk to any way they want to or whatever, and that was acceptable in their neighborhood. Not necessarily by a [Black] 16- or 17- year old that’s growing up. You tell [a teenager] to do something, he might tell you where to go. But, he’d have to pay the price for it if some others are around and hear this. (#15)

In contrast to the other participants, Participant #2 experienced difference uniquely. Participant #2 immigrated to the U.S. during middle adulthood, and noted the difference between life in the U.S. and life in her home country.

“I have seen, witnessed many things here in California, but I says nothing. I don’t belong to here. I say nothing…Segregation is there. I see with my two eyes…There is no segregation in [my home country]. None! So long you work for what you want, you’ll get what you want. You don’t have to deal with anybody…So here, I am not used to segregation, uh uh, mm mmm, because
regardless of who you are, what you are, once you can fill in, you will fill in. That is [my country]. (#2)

Experiencing difference related to observing distinct physical characteristics between the amenities that were set apart for Blacks and Whites, and distinct imbalances of social power between the two racial groups. These experiences were pronounced for the participant who migrated from a country where divisions between races did not take place.

**Being Under-resourced.** “Being under-resourced” was another sub-category of “Being separate,” and further emphasized the differences in resources that were distributed to racially-divided communities. These differences in resources were not just about fewer resources being available in Black communities; participants frequently described differences in the quality of resources that were available as well. Teachers and counselors within schools were frequently described in terms of not caring about the students in their communities, or the students’ academic achievement.

Participant #5 grew up in a racial/ethnic minority community in the northeast region of the U.S. Her adolescent years included being a prostitute, selling drugs, and entering into an abusive relationship that yielded two children and lasted for almost ten years. “I was 17. That’s when I dropped out of high school six months before [graduation]…They didn’t care. I was just somebody that they could cross off the roster” (#5).

Participant #5 described being treated as just a name, stating that the teachers and administrators were indifferent about whether or not she attended school. Another
participant described a similar perspective regarding some teachers in his first high school in South Los Angeles.

Some teachers were a joke...Some teachers were really trying to teach you something. So it wasn’t all teachers...I would tell myself that I want to learn something. I’d go to my math class and they’re going to teach me something new, something I need to learn. I’m going to learn it. I’m going to be up there and I’m going to try to get it. Some teachers wouldn’t even say nothing. They wouldn’t talk to you. They’d laugh and play. A lot of times, we wouldn’t get homework. They wouldn’t explain it to you. Some people didn’t care. And you can sense sometimes that kind of stuff.... I go to school because I want something...I think I wanted more education than I got. And I was willing to get it if I got it. I wanted help with it. I didn’t know who to ask, and some stuff you just keep to yourself...I switched schools...I ended up going over to [a predominantly White school], and I’m so far behind on education. I’m like, “Wow. I don’t know nothing about this. They didn’t teach me nothing over [at my old school]...You have some elementary stuff you learned in the sixth grade, [and] they’re teaching me that at [my old high school].” It was a whole different ball game, and I had no clue. So, now I feel behind. I don’t know what to do now. I didn’t know who to talk to. (#12)

The experience of having a lack of direction in high school was noted by another participant who described not receiving guidance from guidance counselors. By the time he was a senior, he had played three, successful years as a valuable member of his high school’s champion football team.
No guidance counselors came and seeked us out or anything like that. I mean, they came to the games. They supported us. But as far as like, “You thinking about going to college?” Nobody came and did that…in my school, they didn’t do it. I never known anybody to counsel nobody or anything like that. (#13)

Education-related resources were scarce within the schools, and within the community-at-large. Participant #1, who primarily worked as a janitor throughout his adult, working years, described the ways in which his South LA community lacked programs and enrichment resources for students.

They never did do anything for the Black neighborhood--no places for Blacks to go after school, you know…Young Blacks didn’t have nothing to do. You know, they would go to [the park]. That’s the park I used to go to and play basketball and play ping pong, but that’s the only place. They didn’t have many resources to go to, you know, like libraries and stuff like that. (#1)

Participants frequently described the lack of jobs in the community as well.

Participant #1 provided insights into what that did to the community.

Jobs wasn’t nowhere…The only jobs were working at some White man’s or White lady’s house…We had grocery stores in [a nearby White community]. They would hire a few Blacks to work for their chain, but it wasn’t many. A lot of them was prejudiced. I knew they were because by me being a janitor-- I was working at the [market in a nearby, White community]--and a lot of them, they accepted me because I worked there, you know. They didn’t show no prejudice toward me because I’m just a janitor cleaning up, you know. But they was very prejudiced, very prejudiced…It was tension, and that’s what set [the Watts riots] off. Plus the
Blacks wasn’t getting any type of money in their community--you know, programs and stuff like that--wasn’t getting nothing, you know. So, they just said, “Hey!” They just reacted. You know, it was hot that summer. But, it was like--it was really bad. (#1)

Participant #7, a Los Angeles native, provided more details about the Watts riots.

You know what? When that riot was - what was that, …’65? …I was young then. I was about 12 or 13 when that riot was going on, when they were breaking and looting, burning up, whipping people… It was so sad. They was doing a whole lot back then. (#7)

Community members were angry about the lack of resources before the riots. But, the aftermath was even worse. Participant #8 explained why there has been little rebuilding since that time. “You had people who were investors. They were paid insurance [for all the damage, but they] wouldn’t put their money [back in the community].”

Being under-resourced occurred in Black communities throughout the U.S. Participant #15 shared the effect that a lack of healthcare access in the Deep South had on his family.

[Two of my brothers] passed away very sick. One was 17, one was 19. Wasn’t no violence, it was just the year--the doctor was far and between. Whatever illness you had, if somebody in the community couldn’t predict it…you just deal with it. It’s a shame to say that, but that’s the way that it was back in those days. I mean, you could cough, and it wouldn’t be a cold or anything unless you fall down or something. Then they know something is wrong with you. So, they get you up
and sit you in the chair until you fell down…Your family either had to know someone in the medical field—some doctor, or some person that worked in the medical field—in order for you to get attention right away because it wasn’t available to you being Black. That was the general reason. You just couldn’t go to the hospital. You couldn’t go to a doctor’s office unless someone know you or something like that. (#15)

Access to healthcare for Participant #15 improved slightly when he obtained Veteran’s benefits following his military service.

[Veterans’ benefits] weren’t available to you [in my city]. [The VA] would send you to “a” doctor—whichever they’d choose. You’d go apply for medical treatment…They’d send you to a hospital to see “Dr. So-and-So”, and you’d go through the back door, side door, whatever. The doctor would take you and see you, and treat you, whatever. [But], anything you did during that time had to be approved by some individual. (#15)

Being under-resourced for participants included a mix of not having resources available in their communities, as well as having resources that varied in quality from those that were available to Whites.

**Facing Threats**

“Facing threats” was the second major category that encompassed the structural racism-related experiences that participants described, and included two sub-categories—Being warned to stay away and Dealing with intimidation. “Facing threats” pertained to the ongoing risks of harm by law enforcement and members of the White
community. Participants were warned about these threats as children and well into adulthood, and were also given strategies to protect themselves against them.

**Being Warned to Stay Away.** As preventive measures for the threats that participants faced, participants were warned to stay away from, or guard against known risks of social danger. Parents were often the first teachers about how to protect one’s self in the social environment. These warnings included staying away from situations or people who could do the participants harm.

My parents…told me, ‘Don’t drink out of a White fountain ‘cause it’s against the law’…I didn’t want any trouble…You’d might get arrested…Some people tried it and got away with it, but you know, [I didn’t]. (#1)

Another participant remembered his mom telling him and his siblings to stay indoors at night.

Certain [rules] apply for Black people. Like, remember when your mama used to say…“Be in before dark”? After dark, people would get hung. People would get put in jail, beat up by the police. And these were stuff she used to tell us so we could stay safe. (#12)

These warnings did not stop in early childhood. As recently as the 1980s, as an adult with her own family, a participant and her husband were warned about attending sporting events in the northeastern city where her family relocated. This warning was related to the assaults that African Americans often faced by the crowd.

[My husband’s co-workers] said, “When you move there, if I were you, I wouldn’t go to the basketball or baseball games, or any of the games because when the people in the audience start drinking beer or start drinking during the games, they
get rowdy and they start throwing things." What they meant was, Black people are targets when [the White fans] get drunk...A few years before we moved there, my father and my brother used to do like construction work, general contracting work in houses or offices or whatever. And there was a lady who wanted them to go work on her 2nd house, which was in [this same city]. She paid for them to go up and she said they could stay at the house while they were working on it since there was nobody there. There was a bar down the street from there and when my brother and father used to go out to get food and come back into the house, they would look at them, stare at them, and they started calling them names and it was just very uncomfortable for them. So, they took a cab one time and the cab driver asked them, "Are you sure you want to go to that area? Do you know what kind of area this is? I'd be very careful if I were you." Then he said, "I'll tell you what. Why don't you just call me if you need to go out to get food and I'll come and take you? But, I wouldn't walk outside, especially by that bar." [This city] was a very, very racist town. (#9)

**Dealing with Intimidation.** Another component of “Facing threats” was “Dealing with intimidation”. These threats persisted as participants aged. Several years after Participant #14 graduated from college and moved to Los Angeles, she was struck by the intimidation that her mom still felt in their hometown in the Deep South.

Even after I had been [in Los Angeles] for a while, and I’d go home and visit, this [White] woman would call my mother by her first name and all that. I’d get so bent outta shape. My mother would tell me, “No. Don’t you do that. When you
leave, I still gotta live here.” They still didn’t show any respect for Black people (#14).

Participant #14’s mom did not address the persisting disrespect from the White woman. However, another participant did speak up when someone aimed to intimidate him. He purchased rental property in a non-Black community, and received an unexpected phone call.

I bought a triplex…in [a highly concentrated, Spanish-speaking section of] LA. And that’s another issue with prejudice. They do not like us over there …You know, they tried to charge me up? A guy said, “You’re the owner of the property?” One night he called me at 12 o’clock at night. I’m like, “Yeah.” He said, “You’re the one that rent the property over there?” I said, “Yeah.” He said, “You have 500?” “500?” He said, “You live in my neighborhood?” He said “You rent from my neighborhood” or something. I said, “You hold that thought. Where you at? I’m going to come over there tomorrow. I’ll see you in the morning.” Well, …I don’t want to tell the whole story. But, I went over there and met with him. And…I still got my property (#12).

Participant #12 also dealt with intimidation at work. Again, he spoke up. The CEO of the company gave him a “free pass” to speak his mind without the fear of being fired.

I had a problem with a guy…He was over us in the maintenance department…he was a little prejudice dude. And so I’m pushing myself because he wants to fire me … So, we had this big meeting with [the CEO] at the office…[and] all of the people that are over me. They wanted input from the maintenance guys… So I start talking about issues and problems, and I talked about [the guy over me]--
how he talks and calls us out our names…But, I don’t have to be scared. [The CEO] said, “You won’t lose your job, speak up, don’t be scared.” So, I said everything I wanted to say. So now, what’s the problem after the meeting? [The guy over me] told me, “You’re going to be just a painter. You’re going to have the lowest job of all of maintenance.” I said, “There ain’t nothing I don’t do. I do everything.” I was just talking. He can’t punk me.

Conversely, Participant #9 recalled a situation when her son was intimidated by a teacher, and she felt powerless in her ability to respond:

I had a teacher who picked on my son. I remember he punished him for something [my son] really didn’t do--something [the teacher] thought he did--by telling him he could not eat lunch. When I went to the school the next day to confront him about it, he just said, “Oh, I would never do a child like that. I would never tell a child that they couldn’t eat.” He called my son out into the hallway and asked, “You told your mother that I wouldn’t let you eat. I would never do anything like that, I’d never say anything like that.” Of course my son said, “Well, I thought you said not to eat lunch.” “Oh, I would never do that.” So, I had really no leg to stand on at that time because it was doubt when he said I thought that’s what he said. Then several months later, one of [my son’s] playmates was at our house and they started talking about this incident that happened. [The playmate] said, “Remember the time the teacher wouldn’t let you eat lunch?” I was listening and I asked the question about what really happened, and he said the same thing. He said, “Well, ‘So-and-So’ pushed him into this teacher who was coming
up the steps and she went and told the teacher that my son did it, and the
teacher told him that he could not eat lunch(#9).

Participants also dealt with intimidation on a community level. Participant #1 recounted
an experience that occurred during the Watts Riots:

I was riding down the street and I saw these National Guardsmen. They shot a
Black man. He was stealing some rims. That’s what made me go home and stay
in the house...You know, I was tempted to do something. But, then I saw that…I
said, “No, I’m not taking nothing. I’m going home.” (#1)

Participants’ reactions to threats and intimidation ranged from silence to speaking up.

**Experiencing Injustice**

The previous category described participants’ experiences with facing threats in
the community at large, at work, and in school due to their racial difference. This next
category describes participants “Experiencing injustice”. Injustice refers to unfair
treatment that participants described receiving within their communities during their
early years.

Participant #1 was sitting in a courtroom waiting for his hearing when he
experienced the following:

Now I’m out [free], and volunteered to show up for court. I’m sitting in the
courthouse and [the officers] came and got me,…walked me to the back, and put
me in a damn jail until the judge came out…I couldn’t understand it. I couldn’t
believe it….They dismissed [the case]. I’m just thinking about the fact of the
changes I had to go through for selling a box of candy? I never forgot that (#1).
Similarly, Participant #9 recalled a story where her brothers were unjustly detained by the police:

The issue with all of these young Black men being treated unfairly, being killed, being harmed by the police, there were instances in the ’60s with my brothers who were stopped. One of my brothers…was walking with two of his friends just going from one person’s house to another person’s house and the police pulled up and stopped them, told them to get up against the car saying they “looked like” they fit the description of somebody who had done something wrong. And they detained them for a while. They questioned them extensively about something and they had no idea what they were talking about or why. Thank God they didn’t get hurt or harmed, but these police just knew they had the right people, you know…So, it didn’t just start; it’s just now being made public and a lot of people think that it’s something that just started, but no. It’s been going on…Just because it’s not slavery time with runaway slaves, or someone thought this one did something and then they sent out a posse after them – people thought when that era was over that racism disappeared, but no, no, no, no, no. (#9)

In seeking justice, a participant described experiencing injustice when he summoned the police for help.

I had an apartment…My ex-girlfriend, who I was trying to get away from, found out where I lived, came over… She didn’t know which apartment I lived in. I watched her through the window. She said, “I’m gonna tear your car up if you don’t come out here.” So I had to go outside. I saw the police and I told them,
“She’s been breaking in my car. She’s been disturbing the peace.” And they was laughing at me because I’m a kid. I guess what 18, I probably looked 16...So they said, “That’s your problem. You deal with it.” She start laughing and ran in my [apartment]...and they looked like they were pulling off. So, I ran in there and grabbed her, “You’re getting out of my house”...She said, “Let me just talk to you.” “I don’t want to talk to you. You’ve got to get out of here.” And so when I grabbed her to pull her, somebody hit me in the back of my head...I hit him. I did. I took martial arts. Spun around and dropped the police officer, not knowing it was a cop. It was just a reaction. He hit the ground. The other cops walked in and pulled their sticks out. They start hitting me, and I started fighting them...They knocked me from the hallway into my bedroom. I fell over my bed...they hit me between my legs...They did it again and again...It was four White officers. They wouldn’t help me when I called. I ain’t never call a cop since that day. I was 18. So that’s a trip for me. But I can’t have kids from that...I’ve come into a lot of situations [where most people would call the cops, but I chose not to]... It’s like a lose-lose situation in that one right there. (#12)

Another participant described the Mayor who was in office at this time, who endorsed—if not commissioned—brutality against Blacks in South LA. “We had a mayor, Mayor Yorty, Sam Yorty. He was a racist. He just kept the police on Blacks, keeping them oppressed and...You know, beating them, you know like, they was doing the chokehold and all this stuff. (#1)

Brutality against African Americans occurred throughout the country, as well as brutality against White people who fought for justice with them. A participant who grew
up in the South Atlantic division of the United States remembers watching what was happening locally on television.

I used to see in the evenings on the news when I was growing up, you know, the dogs attacking the Black people, policemen standing there looking mean and tough and using water hoses with the water coming out full-force to knock people down, and just beating people. At that point it was Black and White. If they had White people who were fighting with the Blacks or trying to help or trying to demonstrate along with them, they would, you know, circle -- the Ku Klux Klan would catch them by themselves and shoot them or beat them because they helped. And not always the KKK, it was just the so called “rednecks,” you know, just the general population. Not all White people were against the Blacks and it’s the same way today – not all White people are against Blacks. But there are enough of them to be very concerned and to be aware. (#9)

Oftentimes, these civilian acts of violence against Black and White activists and protestors went unpunished. Participants noted that unpunished violence against Blacks persists today. According to their ascriptions, the law still does not protect African Americans in the same ways that it protects Whites.

But does those same rules apply for us, though?... So everybody can stand their ground, but I can’t stand mine?... We got to be more on the political side... We got to get into these laws that they have that where White people don’t have no kind of fear of taking a Black person’s life... We got to get into the legislation. We got to get into where we can put these laws [that say], “If you kill a Black person, you will go to prison ... or get the death penalty”... When I heard [about Trayvon
Martin] I was saying, “Man, it’s a damn shame that in 2012, here’s a young Black kid can’t walk the streets? Come on. He ain’t bothering nobody. He’s not doing nothing suspicious, and you just shoot him? Just because he’s walking the street with a hoodie on? Oh, now Black people can’t wear hoodies? Oh another stereotype? Every Black person that wears a hoodie got to be a criminal? Got to be a gangster? Come on people. Get that stuff, you know. And it really pissed me off to the max. I was so pissed. I’m like, “No!” I really wanted to retaliate in a violent way. But I know better, you know. I know better. It’s not going to solve anything you know…It’s just like, “We don’t care. They’re not human. Take them. Just kill them. They don’t matter.” (#13)

In addition to the anger that contemporary acts of unjust violence have evoked, a participant noted, “For me, it brought up some more pain (#12).

**Protecting Personhood**

“Protecting personhood” is the fourth category that was identified in participants’ ascriptions. This category included ways in which participants described protecting and proving themselves—at times to the detriment of their social growth. For example, after Participant #13 played three, successful years as a vital member of his champion high school football team, the old assistant coach became the new head coach and benched Participant #13 in his senior year. This eliminated his opportunities to play on a four-year university team. When the opportunity arose for him to play in a junior college, he turned it down.

I think at that time I kind of lost my faith in coaches because it depend on what kind of coach you come up with, and I didn’t know what kind of coach I was going
to come against [in junior college. I told my old teammate,] “Even though you told this man I was good…I showed [my high school coach] how good I was. He knew how good I was and for him to do me the way that he did…” I couldn’t go through that heartbreak again… I couldn’t see myself sitting on nobody’s sideline rotting away, you know…To me, I was too talented, you know.” (#13)

In addition to walking away to protect his dignity when there was a power differential at play, Participant #13 also described protecting his personhood within his social network. A female friend of over 30 years accused him of being inappropriate on the dance floor at a party that they attended with their high school friends:

Sometimes you got to be man enough just to walk away…Them is the kind of dangerous kind of women right there who fabricate stuff, you know what I’m saying? A lot of Black men get dimed behind a big old lie. Because I danced up on her. Really? I never touched her. [My friend] said, “No, you never touched her. You never touched her.” I said, “Okay. I know that’s one I need to stay the hell away from.” When I see her coming, I know to go the other way now. (#13)

In contrast to #13, who walked away to protect his himself, Participant #12 chose to speak up in order to protect his social self.

I just started working there…And there’s a gang there. You can see it. It’s obvious to whoever walks through there...So [the management company] went out and made me some flyers….to let [the tenants] know that I’m the new manager…So I took my friend with me because I was excited I got this job. There’s this little problem with [the gang], but I’m excited about the job…When I get there, [the gang is] holding a meeting outside it seemed like. It’s about 12 of
them out there. I heard them say, “That’s the [dude] right there”...and [I] heard somebody [else] say, “Oh, that’s him? I’ll whoop his ass”... And I was like, [to my friend] “You heard that?” He said, “Yeah”... So, since he heard it, I got to go address it because you know, we’re men. We don’t want to be no punk. But if he didn’t hear it, I would have probably never addressed it, you know what I mean? (#12)

Participant #5 returned to her old town to prove herself to a naysayer in her life. I remember I was a CNA [Certified Nursing Assistant], and I told my White teacher that I wanted to go back [to school] to be an RN [Registered Nurse]. And she...looked down at me as if I’m nothing--“You’ll never be an RN.” And that was the best thing that she could’ve said to me. And I said, “Well, why can’t I be?” And I knew that it was racially motivated for her to say that. It wasn’t because I wasn’t a good CNA, it was because I was Black…I was determined to prove her wrong. And when I graduated, I went and found her, and told her, “You know what? I’m an RN”. Because I did not want her to feel like she had that much power over me because she was White and I was Black, and [that] I didn’t have choices like she did (#5).

Summary

In summary, the structural racism context was described in terms of being structurally separated from Whites according to laws, physically separated through residential segregation, and experiencing inequitable differences in resources and power. Participants experienced potentially avoidable loss due to their families’ lack of
access to healthcare, and their lack of access to a quality education with quality teachers, counselors and educational resources.

The context also included warnings from family and community members about such things as staying away from “White’s only” areas because something bad would likely happen to you; being in before dark because something bad can happen to you when night fell; and, in more recent history, not attending professional sports competitions or walking in certain neighborhoods because you would likely be assaulted for being Black. Heeding the warnings to stay away was not always possible, however, as participants dealt with intimidation by community members, law enforcement, and others in their day-to-day lives.

Additionally, participants described experiencing injustice—oftentimes by the criminal justice system. Unpunished acts of injustice were initiated by sworn officers and civilians alike. Consequently, participants described acting in ways to protect their personhood. These ways included staying away from people or opportunities, as well as defending their social identity at the risk of their personal good.

**Identifying Meanings about Structural Racism-Related Experiences**

The second aim of the study sought to identify meanings that participants associated with the structural racism-related experiences that they described. Three major categories were identified—(1) Being outsiders, (2) Needing to Level the Playing Field, and (3) Needing to take care of self—and several sub-categories (Figure 3). These categories encapsulate the understanding that was generated about the participants’ social position as a racialized group, and an understanding about their need to advantage themselves as the racial group that was situated on the lowest tier of
the social hierarchy. The three major categories identified what it meant to be in an inferior social position, as well as participants’ aims to promote themselves as they lived within an oppressed social context.

Figure 3. Meanings about Structural Racism-Related Experiences

**Being Outsiders**

The first category, “Being outsiders”, represented the meaning that participants associated with being isolated from, and treated differently than Whites. Four sub-categories were identified that amplified what being an outsider meant—(1) Not belonging, (2) Having less social value, (3) Losing Hope, and (4) Being mishandled.
**Not Belonging.** The sense of not belonging was associated with feeling like African Americans were not welcome and did not fit in with Whites.

All and all, the [White] community themselves, all they had to do was just call [the police on you]…Your community was just your side of town, as far as they was concerned, you know. The Whites would tell you, “What you doing over here, boy.” That let you know that you ain’t got business in that part of the community.

(#15)

This sentiment was echoed by another participant. Although residential segregation has been abolished by law, Participant #1 suggested that the ideology of Blacks not belonging in White communities persists today.

As the years went by, Blacks started moving in the neighborhood, Whites started moving out. All the White people just moved out completely. I always wondered why Blacks and Whites cannot live together in the same neighborhood. You ever think about that? What is the problem? Is it lack of education, or what? I always wonder why White people just don’t want to live around Blacks, unless you’re a celebrity or something, you got money. But, other than that, they don’t want to live around Blacks…It’s like that. I still think it’s like that today. (#1)

Participant #12 described internalizing the feeling of not belonging, and wanting to fight against it:

I used to feel that--I’d go somewhere that’s not [with Black people] and I would feel like--I’d feel like I didn’t fit in. Sometimes I’d be looked at like, “What are you doing here?” [I would think], “I got money just like y’all!”…I wouldn’t say that
they’re ever better, but they feel like they are. They look at us like we’re nothing, and I could feel that. (#12)

**Having Less Social Value.** Having less value included being seen as tainted and disposable. Participants reported that this lower social estimation was reinforced in everyday life, and institutionalized through misrepresentations of African Americans in the media.

People look at African-Americans differently no matter what we do…We get that stigma on us… like they show us on TV. Like we’re loud all the time, and we don’t know how to talk. Every sentence is like “You know what I’m saying. You know, you know?”…It’s like they’re searching the crowd to find the one that they know can’t answer the question with sentences, who can speak. They get the one… I hate that (#1).

Participant #9 felt that low-income, African American patients were stigmatized where she worked.

One lady that I used to work for was a pediatric [specialist], and I had to schedule patients for her…She would set aside one afternoon per week from 1-4pm for “welfare patients.” That’s the way she described them. She claimed “those people” would always come late, they wouldn’t call if they weren’t coming, and they would mess up her schedule. So, she would schedule every 1/2 hour for “those people,” but for everybody else during the week, it was an hour appointment.
Participant #15 talked about Blacks having less social value as demonstrated by military recruitment strategies during the times of World War II and the Korean War. When I say that we—the younger [Black] generation—was sent out to war, people would say “Go out and you’ll be a better person, or we’ll make you a better person.” It was more like you didn’t have no choice…You go to war so that way they can keep their kids in school, and still fill that spot…If they needed 500 mens out of one state—don’t mean they got to have 200 Whites, 200 [Blacks]…That means they can all be Black. And that’s what they were doing back then. And when I say the doctors, and the lawyers, and the social clerk and everybody else—their kids, they keep them out and send me in.

According to this participant, Black teens and young adult men were targeted during military recruitment during the times of war, and told that their lives would be improved by enlisting in the service; but, Whites protected the lives of their own by filling their spots with African Americans.

**Losing Hope.** As outsiders, participants described the hope that Dr. Martin Luther King, Jr. brought to Black Americans as their leader and voice. He was perceived as the one who would help lead Black from the margins to mainstream society. He helped narrow the distance between Blacks and Whites by working to temper the hostility towards Blacks, and by fighting for equity and justice. When he was assassinated, that hope died and people were angry. Participants described the feeling of hopelessness that followed Dr. King’s death.

“Once [Martin Luther King, Jr.] was killed, it was like you lost leadership. You kind of lost leadership and you will never have another leader like that, you know?” (#8).
“The community just felt hopeless” (#1). According to Participant #9, this sense of devastation resulted in community-wide acts of desperation:

After the assassination of Martin Luther King, a lot of people were devastated.
And because of that, they felt like they had no leadership anymore, and all the years, all the work that Martin Luther King had worked so hard for, it’s like they were angry and then they would riot, they would loot, destroying a lot of the Black businesses in the process…I remember the National Guard being at the corner of my street. I didn’t live far from an area that was heavily looted. There were lots of stores and shopping areas that were in our neighborhood, and they totally destroyed the stores there. I mean, senselessly taking merchandise from these people, but they were so angry and just felt lost, I guess, with no leadership any more. You know, Martin Luther King is gone. What are we going to do now? Who’s going to look out for us now?”

In response to this widespread sense of hopelessness, participants talked about celebrities and activists who took action to empower communities.

[Civil rights leaders] was trying to help everybody… to get better jobs…where the Black people could get out and work for themselves. Like James Brown said, “Open up the door and they can get it for themselves.” That’s why he made that record. (#7)

Participant #1 also described what community leaders did to get the community going after Martin Luther King Jr.’s assassination and the Watts Riots.

If it wasn’t for guys like…Stokely Carmichael, Edridge Cleaver, H. Rap Brown…somebody had to get up and stand up and say, you know, do something
because...if it wasn’t for those guys...the benefits that we get today wouldn’t have happened... I didn’t believe in the...violence, you know. But, they were really the ones that set the pathway, in a way. That’s my opinion. If it wasn’t for those guys, we still probably would’ve been like, with [the White’s] foot on our neck, you know. (#1)

**Being Mishandled.** Despite the social progress that occurred around the time of Dr. King’s death, participants described being similarly mishandled (i.e., not being taken seriously, being misused, and being misrepresented) many years before and after his death. Participant #12 talked about feeling mishandled at school. “If I have a problem and I want an answer, [the teacher would] make a joke about it...I never raised my hand again...[I thought,] ‘You ain’t gonna keep clowning me.’” He also described feeling misused by his employer after working for them for years, and putting his life on the line for them in the process.

I felt I was misused. You can use me, but don’t misuse me. Misuse is something you’re doing that I’m not really allowing you--that I wouldn’t want to happen to me. If you’re misusing me, you’re doing something wrong to me...As soon as I start cleaning it up [and get all of the gang members out]...[the management company] throws somebody over me and tells me [they’re] going to pull me out. “I was just there to clean it up for you? You should have told me. I would have still cleaned it up probably because I like you guys, but let me know what I’m getting into. Because I put myself out there for a lot of stuff...Let me know what’s going on. I trusted you guys up ‘til that point.” (#12)
Similarly, Participant #15 described being misused in the military. Despite Black soldiers putting their lives on the line during war, their health statuses were overlooked—unless there was a risk that they would infect others.

[When I was in the military], health wasn’t a part of it…You was given orders, duties to do. And those, your chores, you had no say-so. Those are chores in which they had assigned you to do—they expected you to do. So, you tried to fulfill your expectation…regardless of how you felt. So that’s what you went by…[Medical care] was available in the illness aspects of your life…If you have anything that could possibly spread, they do a follow-up on that—diseases anything like that-- because they don’t want you getting the other parties ill, too. But as far as your welfare is concerned, if a cup of water will get you out there to do your work, you get a cup of water and get out there and do it…You ain’t going on light duty or anything like that. If you able to function, you’re gonna function, and that’s what they expected out of you.

Another participant addressed how African Americans have been misrepresented by the media—particularly during the Watts and Rodney King riots:

“[Blacks] didn’t burn them out, they just looted them…And it was Mexicans taking advantage of it, but you know who got the blame? Blacks get the blame. Just like this last riot. We got the blame. So this is what I witnessed…They [only] showed Blacks on TV. It wasn’t only Blacks taking advantage, it was Mexicans doing it, too. (#1)

According to these participants, feelings of not belonging and having little social value were grounded in experiences where African Americans had been treated badly on a
social level. Participants described feeling like outsiders from the time of adolescence through older adulthood.

**Needing to Level the Playing Field**

“Needing to level the playing field” is a major category that has two sub-categories for achieving it—(1) “Being watchful” and (2) “Joining resources”. Needing to level the playing field meant that participants recognized that they were socially disadvantaged and perceived as racially inferior. In response to their social position, they had to find ways to advantage themselves in order to survive this social context. Leveling the playing field included implementing strategies to help advantage themselves within their social environment. The two sub-categories were strategies that participants described.

**Being Watchful.** There are two properties of “being watchful”. First is its constancy because structural racism is ever present; second is its difficulty because structural racism is ever changing. Participants described maintaining a heightened awareness about underlying motivations and intentions when interacting with Whites in their roles (e.g., as police officers or teachers), and as consumers of White businesses within South LA communities.

For instance, participants described thinking critically about what they were being told.

They teach you their way…and that’s how they kind of play on your [mind]…I never wanted to get caught up in that restriction where I’m thinking...like they always say, “White is always right.” I even questioned a lot of things…[for example] because this word says this, is that what it really means?... I’m like,
“Who gave you the right to say this word means this, this word means that?” It’s a lot of things like that I think about. I’m constantly aware. (#13)

Being watchful included being cautious about the products that are put in the stores in the Black community.

I got to watch them... even if they sell me something in the store. When I was a teenager, I didn’t drink a lot, but my friends drank a lot of beers. They would get beers 2 for a $1. I was like, “Why y’all buying that? They put it in this neighborhood and giving it to you for 2 for a $1, and y’all jumping on this stuff. Something is in that beer!” I would doubt stuff like that. (#12)

Needing to be watchful also included being on guard when it came to the police, who most participants described as looking for any excuse to act when it came to Black people. Participant #1 recounted an experience when he was 16 years old and made money by selling candy door-to-door.

I was selling candy and...I didn’t see the police. But, I made a mistake and accidentally went in a [neighboring city]. You know how you have to look at the street signs? I wasn’t in Los Angeles and I didn’t know it [when I crossed the street]. I went over there and I went to knock on this door and this lady, she started looking over my shoulder, and I turned around and the police was out there. And I didn’t make a sale there...She said, “No, honey. I don’t want no candy,” like that. I went back down the steps to the street and they put the handcuffs on me and arrested me...for selling candy in a different city, when I should have been in Los Angeles, you know. And I said, “I’m just selling candy.” They took me to jail... And they got me in there and they booked me and one
officer said – and I never forgot this. He said, “Where you keep the bennies at?”
He thought I had dope all in my collar, you know. They thought I had some
dope—drugs and stuff. “Where you keep the bennies?” I said, “Bennies?” I said,
“I don’t have none of that.” (#1)
Participant #12 described needing to watchful of healthcare providers.
I was listening to [my previous doctor] and he [was] killing me. He’s giving me all
this stuff, and then some of these pills kept my weight up, I found out…When I
went to [my most recent doctor], he told me “You don’t need these.” Took
everything away and just gave me [one pill], and I felt better. I felt good, you
know. (#12)
Needing to be watchful also referred to being aware of hidden expressions of
racism. For instance, Participant #7 talked about some Whites hiding their true beliefs
about African Americans.
There was some White people back in them days, they didn’t care for no Black
people. They wanted to whoop them and beat them, make them say, “Yes, sir”
and “Yes, ma’am” and all that…Yeah, they still wear them sheets and hide
behind them. (#7)
Another participant described the hidden nature of racism in more systematic
terms. “You can’t really put a finger on it because it changes. They’re so
conniving…They can just run and change…the racism…As soon as you put a finger
here, it changes. It will be something that hides in the system” (#12). Participant #8
offered a similar ascription in terms of an experience she had when looking for housing.
They still wearing sheets today, just in other ways…Let’s say housing…They have it advertised …And so, when you call and say, “I want to put in this application for this apartment,” and you sound like you’re Black, [they say] “Oh, that’s been taken already”… I know a place where I was trying to get some housing, they had on the outside “Housing for Seniors” and we went and applied every day, we went and applied. The one that was the manager, she wasn’t White. I don’t know what she was. She wasn’t Mexican, and she wasn’t White so I don’t know what she was, but she had a nasty attitude. “Well, I don’t have anything right now”, but she gave this guy an application and said, “I’m going to give you an application.” And we had been coming every time to get this application…Yeah. Gave this guy an application. I said, “How come you gave him an application and he just walked in here a few minutes ago waiting with me?” (#8)

Needing to be watchful was a strategy that Participant #13 described as a tool for leveling the playing field so as not to be controlled, taken advantage of, overpowered, or put in a position for experiencing injustice or intimidation.

It’s all about, as I always say, learning how to play the game. Learning how to play the game is understanding exactly what the game is…It’s always that strategic move you have to make. You got to be careful when to move and when to stay still, you know. Like I said, you have to really be paying attention to everything that goes on around you. (#13)

According to this participant, you make the playing field more level when you learn what the game is, and when you are conscious of what is happening around you.
Joining Resources. Another strategy participants used to level the playing field was joining together with others and joining resources as tools to survive. For example, soon after moving to Los Angeles as an older adolescent, Participant #6 leveled the playing field by soliciting support from two Black men who he did not know.

I [almost got] attacked by some skinheads once. I was in a [predominantly White area of LA]. I was about 20 [years old]. It was about seven of them. They said something--they called me a “nigger” and I blew it off …So, they started walking behind me. I could hear the footsteps. I have a very—personal space. You enter my personal space, and that’s when I start to go crazy. But, until they enter that space, I just said, “Let me walk faster.” But, as I walk faster, they walk faster. As I kinda trotted a little bit, they almost acted as though they were gonna chase me. Now, this was in broad daylight…I saw two other Black guys, and I just kind-of ran over there. And when I ran over there, for whatever reason, seven White guys after three Black guys wasn’t an even match. So they stopped, and we just kind-of walked after them for a little bit, and then we just kind-of let it go. But, them guys—they didn’t want to mess with three of us. (#6)

Similarly, Participant #13 told a story when he and his brother supported a teammate who was afraid to walk home from school because a gang threatened him.

It was all about us coming together and playing as one...Everybody watched out for each other… Off the field, it’s the same. We watched out for each other. I remember one of my teammates, he had to go home, he was going home and he was so scared. Me and my brother asked him, “Man, what’s wrong with you?”…He said, “Man, when I go home, these guys are going to be waiting for
me and they going to jump on me”…So me and my brother walk him home…The
guys [from the gang] for sure were standing out there waiting on [my
teammate]… So we go to the [gang members] and we tell them, “Hey, Man. You
can’t beat up my boy… and we ain’t talking about just today. Leave him alone
forever”… Came back to school…[The teammate said] “Man, I don’t know what
y’all said, but those guys don’t mess with me no more”… And we get together
today and we talk about that…He say, “Yeah, Man, I remember that… I
remember y’all walking me home, Man. You know, Man, I appreciate y’all to this
day”…We watch out. Even like now to this day. (#13)

With the help of others, the participants described being on more of an equal ground
with those who posed threats to them. Based on their conclusions, when that playing
field was level, there was a more positive outcome.

Two participants described how their communities joined resources to meet one
another’s food needs.

In our neighborhood we raised gardens. You didn’t know anything about going to
the store buying greens and all of that. Everybody had gardens. What you didn’t
have, you traded with your neighbor… That really had a lot to do with the
economy for people. You didn’t have to go out and buy food. People didn’t know
a thing about, you know, going to the store and buying canned this and canned
that. You traded with your neighbors and stuff. (#8)

Similarly, Participant #1 stated, “My neighbors, they was poor, but we all got along with
each other. We would borrow things from each other like, one neighbor might want to
buy some flour or syrup or something like that, you know, and we’d help each other out”
Participant #2, described a similar practice of joining together with others in her home country—a country which she described as “poor”.

We help one another. I can go to your house and say, “Would you please give me a cup of flour? Would you please give me a little bit of salt?” That’s my country. “Can you help me with a little dollar?” That’s what they call it—a little dollar, and our dollars are the same. “Can you take care of my child? I’m going out.” You would take care of that child. You don’t charge because you are neighbors…in my days of growing. (#2)

Beyond meeting basic food needs, Participant #8 described the power in communities coming together for social change. “I really think when you get the poor people together and speaking up for the poor people, it just about would have run [Martin Luther King, Jr.] for president” (#8). Another participant described joining resources with a friend to support one another in building wealth in real estate.

[My friend said,] “Man, I figured it out. I quit my job.” He’s a millionaire now...He had bought a four-unit building, and I fixed it for him. And then he bought two, four-unit buildings and a 12-unit building, and I fixed [them] for him… So I fixed it for him because he knew nothing about that part. And I knew nothing about property, so we came together. I fixed it. He made money off of it. I gave him a low price—cheaper probably than any company because I’m his friend, and I want to see him succeed. (#12)

Participants described joining resources when threatened by violence, to meet one another’s basic survival needs, and to help support one another’s socio-economic mobility. Joining resources was about survival and about strengthening one’s self with
the collective power of their community. Joining resources was a strategy that helped participants and their communities to level the playing field—i.e, to advantage themselves within a structurally disadvantaged social environment.

**Needing to Take Care of Self**

The third major category that related to the meanings that participants ascribed to their structural racism-related experiences was the need to take care of self. Four sub-categories were identified, and they included a transition the reflected an awakening to self, and three strategies: (1) being independent, (2) taking action, and (3) taking ownership. Participants were nearing, or in young adulthood when the awakening occurred.

**Awakening to Self-Power.** This transition is significant to note because it marked a turning point. It reflected an internal shift that occurred within participants. It was a realization that they were able to stand in their power; that they could take action for themselves, by themselves.

For instance, Participant #15 awakened to the potential of his power via his exposure to opportunities in the military.

As I grew and [saw that] a lot of people was coming back out of World War II—a lot of men and younger men was coming back out of service, and the manner in which they would conduct themselves, this gave me something to look forward to. And to get this would mean that I would have to get in the military to do it. So, those were my ambitions, and that’s what I sought…Those that came back from World War II—a lot of them came back proud of what they did for their country. It
meant that they got better respect being a veteran than they did before they left.

(#15)

When Participant #15 became eligible to enlist in the military at age 16, he did.

Participant #5 awakened to her self-power when she pushed through nursing school. The odds of finishing school were greatly stacked against her.

I had two children, and I’m getting $181 a month from welfare for me and my two kids... And I said, “I don’t want to live like this. I don’t want to raise my kids like this.” So, I decided, “Okay, I was going to go back to school”... I said, “I don’t want this kind of life for myself. I don’t want this for my kids. I don’t want to raise them like that.” So, I went to school. I would ask my mom to babysit my kids. She would be like, “You had them. You raise them.” She wouldn’t watch them. So, I had an older cousin across the road—we called them MaMa and PaPa. So, MaMa always watched the kids for me while I went to school... And so their dad, the last year of school, he was like, “You need to quit school and come work in the factory with me.” And I’m like, “No.” He’s [physically, verbally and emotionally] abusing me and everything. And I knew this was not something I wanted... my catalyst for [getting through it] was my kids...and I knew I had to do it. I couldn’t rely on anybody else to do it for me. So, I stood up against their father who said, “You can’t do this” and tore up my nursing books. And I said, “No. I’m not going to let you stop me from doing this.” (#5)

Participant #12 described when he awakened to his power. Unlike many of the stories that he shared, this realization came without any reference to having to prove or defend himself through violence or aggression.
[My boss] was tripping because I had a house. I thought everybody had a house. I thought I’m down here; they’re up there. But I’m just tripping. I learned something from that…. [I learned] that I ain’t always down at the bottom like I thought I was--because I always think I’m the last person on the totem pole.”

(#12)

Participant #13 awakened to his self-power based on an experience in one of his high school classes.

He was a Black teacher – African… He said, “Man, come on. [You and your friend], stop giving me a hard time because y’all are the leaders in here. Everybody is going to do what y’all do.” And sure enough, when him and I straightened our act up, everybody come and fell in line. And I was tripping like, “Man, this is crazy.” I never knew I had like a leadership mentality (#13).

He awakened to the idea that he was a leader. He was not a follower; he was not a victim, and could take responsibility for himself. “I don’t want to sit back and go, “I blame the White people” because all we doing is suppressing ourselves. So I can’t look at what they did. I just got to learn how to play the game” (#13).

**Being Independent.** Being self-empowered made room for participants seizing opportunities to be autonomous in their lives. One strategy for taking care of self was being independent and not wanting to be taken care of. “I want to be independent. I don’t want to ask nobody to do nothing” (#7). Likewise, another participant described wanting to stand on his own feet without needing to ask others for help in the way that he saw some of his adult male family members do.
I watched [some of] my uncles. All they did was paint. And when it was nothing to paint, they had their hands out. Well, I don’t know how to put my hand out. I don’t know how to ask nobody for nothing. So I said, “I can’t do that. I can’t be like them. I don’t want to be like them.” I don’t care what I do. I’m just not going to have my hand out for nothing. (#12)

Participant #12 also described being independent in terms of being “normal”.

I want to have a successful life. At the end, I want to say, “I did it and it worked out.” I want some more stuff. I want to take a longer vacation. I want to go further... I want to be normal. I want to do some stuff... Like when you vacation, I don’t want to be the one that can’t get in a kayak and go around the water because I don’t have enough money or something. So, I make sure—I don’t want that to be the reason, you know. So if I go somewhere, I’m going to make sure I’m straight. I’ll make sure I have what I need so I can feel normal. (#12)

Participant #13 stated that being independent meant being self-reliant and responsible. “It’s what I know. It’s where I put [myself]... just being [your]self... taking care of yourself... [being] responsible and [paying] your bills.” (#13).

In keeping with the idea of being responsible as a component of being independent, Participant #15 talked about being responsible today, so that he could enjoy tomorrow.

Those of us in the military, we came back a different person as far as life was concerned—very different. Meaning that before then, life was today and if death tomorrow, so be it. But after the military, and after what you’ve been through and the fact that you’ve been paid, what you’ve learned and everything, life is more
you work today for tomorrow. So, if you live for tomorrow, you want to enjoy it.

And so that means that you stay off the corner, get you a job, buy you a car, buy whatever things you want in life.

Essentially, by being responsible, and taking care of yourself today, you can take care of yourself and enjoy your future.

**Taking Action.** Another strategy for taking care of self was speaking up for self and loved ones. Developmentally, participants were well into young- and middle-adulthood when these experiences occurred. For example, when Participant #9 was working as a scheduler in the pediatric office, she spoke up on behalf of the patients who were marginalized by the physician.

To me, as a Black person and one who is not wealthy, that seemed very discriminatory, and I reported [the physician] to her supervisor...I couldn’t—not in good conscience if their child was having a problem—I couldn’t wait a couple of months to bring the child in just because there were no openings on that one afternoon between 1-4pm. It was full for months at a time! I didn’t think it was fair, so I would schedule them whenever I had an opening. [The physician] would get upset about it, but so be it. I just couldn’t treat people that way. (#9)

Participant #13 spoke up to his manager at work who was threatening him.

One time he told me, “If you’re going to keep doing this, I’m going to fire your ass.” I said, “You know what? You’re going to have to do what you’re going to have to do; and, I’m going to have to do what I’m going to have to do.” And when I told him that, he said, “What?” I said, “You heard what I said.” I said, “You’re going to have to do what you got to do, and I’m going to have to do what I got to
do.” So when I told him that, he looked at me, shook his head and walked away.

He knew he was in violation—especially when you threaten me like that. You can’t threaten me on the job. And I’m letting you know.” (#13)

Another participant had a similar experience at work. Other Black people were getting forced out of their jobs, but Participant #2 stood up for herself. “If I were a weakling that I do not stand up for my rights, I too would have been pushed out like the rest” (#2).

Soon after re-locating from the North to the South, Participant #5 witnessed the myriad of ways that Blacks were still oppressed in her southern community. Shocked by this revelation, she took immediate action when she thought that her five-year old son’s teacher was mistreating her son:

When I went to the South…I saw how Black people were treated and talked to, [and] I was shocked! I was like, “Oh no!” I would go in the bank and I would see Black people wouldn’t have eye contact with the tellers. Or, they would hold their heads down. I was like, “uh uh”. I remember putting my son in school. And he had a White teacher, and apparently he had not done something right, and she pinned a note to him and sent it home. And, I was livid! I went to the school…I’m young, probably early 20s. And I yelled at that White woman so bad she went home with a headache. I said, “Don’t you ever pin something on my child and send him home…“You got a problem with something, you need to call me and you need to talk to me.” I lived there like, “You know what, I’m not going to let these White people mistreat me like they did my relatives.” I was going to take a
stand—not knowing that I probably could’ve been lynched. I just wasn’t going to tolerate it. (#5)

**Taking Ownership.** A last strategy for taking care of self was taking ownership of one’s self and one’s space within an environment that was structured to limit and control the participants and their fellow community members. Taking ownership was both literal and figurative in the purchasing of property and in taking control of one’s situation and future.

Everybody around there [in Watts] owned their own houses. Some people don’t believe it, but there were Black people who had houses and rented them out. They were homeowners, but they rented out to other Black people, it didn’t matter what race. They just rented them out, but they were the owners… They bought a whole 3 or 4 of them, and they bought them. It was easier for them to buy houses then. So they bought them and then they stayed on the property. (#8)

Even though it was a devalued community, they still took ownership and found value in it for themselves. Similarly, after working for several years with his friend who built wealth by purchasing multiple rental properties, Participant #12 aimed to follow suit.

Four or five years went by…I start telling him, “Man, I want what you want. I want some property too.” [He said], “Clean your credit!” I get mad at him…I don’t know what “clean your credit” means. [He said], “It means you can get you some property” …I paid everything off. Then I said, “I need some property. I paid off my stuff.” He said, “Come on, what you want?” We got some places, and got me a property… He kept his word. (#12)
Although Participant #2’s home country was not structured to advantage some and disadvantage others, she stated that her community was poor. Taking ownership of her space in her home country was a symbol of pride. “I have my own property. I work hard, and I owned my own house…four bedrooms” (#2). She described the experience of ownership in her home country in comparison to currently renting property in Los Angeles.

I sit here going through all kinds of nonsense with people because rental is not my cup of tea. In my own country …the paradise—I’ve been in my one house over my head. I need no constructor. I construct my own house over my head, me and my son. My children, me and them, we make cement so that we can put the foundation for our house. Mm hmm. I build my own house. (#2)

Participants also described a sense of duty, pride and self-reliance in describing their experiences with taking ownership. This included using whatever they had (or had access to) in order to take care of themselves.

My father taught me things. He taught me responsibility—not just by talking to me all the time, but just showing the things that he did…He led by example. He’d go to work, and man he’d bring that check home and give it to my mom. Now he wouldn’t take nothing out of his check…He had other kind of things he could do, like he could work on cars. He could work on houses. So my daddy was always hustling. Once he finished his job, it’s like it never stopped. He just kept going and kept going. So he would go out there and he’d fix cars; he’d do tune-ups; he’d change oils; he’d do brakes. That’s his money. “But I know I took care of my
family. I took my check home to my wife. She can take care of my kids and stuff like that.” He didn’t take no money out of that. So that gave me a sense of value. You know, it’s like, “Okay, that’s how I’m supposed to be. That’s what I’m supposed to do when I grow up.” (#13)

Taking ownership also meant that participants refused to be stopped by threats to their social position or personhood.

To hell with racism. I’m not going to let it affect me. I’m still going to do what I got to do, but I’m aware. I’m not going to say it does not exist. But, I’m going to look and see to make sure I’m in the right position where I’m not going to allow it to hurt me or anybody in my family, you know. And I’m not going to do anything stupid. (#13).

Participant #5 took ownership of herself by reading.

“I read a lot. And I had to do a lot of building myself up because I didn’t have a lot of people that were saying these things. I had instructors saying I couldn’t do anything. I had an abusive husband who said I was nothing and I was never going to be anything, and that nobody was going to want me. So all these people around me—my mom, “You got these kids, you raise them.” You know, and not really saying, “Well, I love you or I’m proud of you… After a while I just had to read and figure out how I can empower myself because I wasn’t getting it from anybody else” (#5).

Participant #15 took ownership of himself by following in the footsteps of men in his community who seemed to return from the military with better life chances.
On my 16th birthday, I was in the military. Back in those days, that was an escape from that type of living—that type of environment. I knew that there were better things in life for me than being under this kind of...condition. (#15)

Summary

In summary, one meaning that participants derived from being separate from other races, facing threats, experiencing injustice, and needing to protect their personhood was that they were outsiders who did not have the same social value of other races. They also had the sense that they did not belong, and were acutely aware of their social mishandling by the police, by teachers, by employers and by the media. With the shake-up of the Civil Rights Movement when Dr. Martin Luther King Jr. was assassinated, and the subsequent riots throughout the country over the years, participants described a sense of feeling lost and discouraged. Consequently, they felt a need to learn and apply strategies to overcome the devastation and survive.

Injustice and inequality were so deeply embedded in the social environment that participants had to learn and apply strategies that would give them a level ground on which to overcome being oppressed and limited. These strategies included looking out for hidden ideologies and ill-intended actions by those who were seeking to advance race-based oppression in changing ways. It also included pooling resources with others within the community to meet their basic needs.

Despite the contexts within which these participants felt like outsiders with little social value, there were select family members, friends, neighbors and leaders who provided support and encouragement that led to a positive sense of self and a belief in their own abilities. Participants discovered their own self-power and aimed to take care
of themselves. As they settled into the notion of being independent of the limitations structured by their social context, they spoke up, took action and claimed ownership by providing for themselves.

**Being Diagnosed and Learning to Live with Diabetes**

This section addresses the third aim of this study: to identify meanings that AAOAs with uncontrolled T2DM ascribed to their diabetes and diabetes self-management. Thirteen out of 15 (87%) of the participants were diagnosed with type 2 diabetes in middle adulthood. One participant was diagnosed in young adulthood, and one during older adulthood.

Participants described three distinct experiences that revealed the meanings and processes that had helped them to live with diabetes. The experiences made up the major categories: Fearful anticipation, Learning to live with it, and Taking control. The sub-categories represent the meanings, processes, and strategies that participants related to their diabetes-related experiences (Figure 4).
Figure 4. Meanings about Diabetes and Diabetes Self-Management

Fearful Anticipation

Upon diagnosis, participants perceived diabetes as something to fear. With ascriptions that ranged from concern to panic, all of the participants described diabetes as a threat that they anticipated would limit their lives in some way.

Fearing the Unknown. Participants felt threatened by diabetes because they didn’t really know what it was or the impact that it would have on their lives. “Diabetes is something that don’t nobody want to hear. They find out [they have it] and think, “My leg!” (#15).

Another participant thought his life was about to end.

I called my mama because I knew nothing about diabetes. It felt like cancer and I had three days to live….I was like, “Mom, I don’t know how to tell you. But, I have
diabetes and I don’t know how much time I got”…I’m thinking I’m going to die because I had no clue what diabetes was. (#12)

Participant #2 said, “[Diabetes] frightened the hell out of me.” Participant #1 called it “sneaky” and “very, very scary.”

**Feeling Overpowered.** Participants used words that implied feeling overpowered and defeated when they were told that they had diabetes. Participants #5 and #7 said that learning that they had diabetes made them “depressed.” Another participant felt broken.

It was devastating to hear that I was diabetic…. I felt like both wings were broken. Like, uh, my ego. You get one broken, you kinda limp around. You have both broken, … [lowers head and shakes it]….it’s something I don’t want to think about it. (#4)

**Having Thing Change.** Participants described feeling changed by diabetes. These changes had occurred in both a physical and psychological capacity. “Your life changes as a diabetic. My eyes aren’t any good anymore. I can barely see… That is something I will never get back because of diabetes” (#11). Another participant noticed that his body had changed.

I like martial arts, boxing. I used to play football. I ran track. I was in shape. I worked out [when I was younger]…But, I noticed I started to gain extra weight in my gut area. I started feeling a little lazy…I feel like I don’t want to do everything I used to do. (#12)
Despite having severe asthma, another chronic condition that he had and had controlled successfully throughout his life, Participant #4 questioned whether or not diabetes was something that he could control.

    My confidence level has dropped…. Confidence in being me and the things I want to do in life, you know. Having some big concerns about my health. The asthma is controlled, you know. This [diabetes] here is something they say it can be controlled, but I wonder. (#4)

Participant #3 felt like her relationship with her doctor changed. “I felt like my doctor blamed everything on diabetes. If I came in for anything else, he just went back to me not doing what I was supposed to be doing for my diabetes.” Before being diagnosed with diabetes herself, another participant noticed how diabetes changed her brother. “My brother had diabetes and it changed him. It seemed like he just gave up on life when he found out that he had it. I don’t know if it was having to take insulin or what. He was just never the same.” (#5)

**Learning to Live with It**

    Upon diagnosis, participants were often shocked and felt afraid when they learned that they had diabetes. Over time, they underwent a process of understanding what diabetes was, understanding how they ended up with the condition, and learning to live with it without experiencing diabetes-related complications.

    **Attributing a Cause.** Participants attempted to attribute the cause of diabetes now being present in their lives. Participant #2 sought understanding from her doctor about what diabetes was. She never heard of the condition before migrating to the U.S. as an older adult.
I ask [my doctor] at the [clinic] because it’s there I went for a physical. Will you please tell me what [diabetes] is? How does it come about? I really want to know because when I was back home, I had no knowledge of these things.

Another participant believed that he got it from stress.

In the Black community, the only thing you knew about diabetes--because they called it sugar-- “You got sugar.” And that’s all you knew. I wasn’t thinking that I was going to be a diabetic… I went back for like a follow-up and I think one of the nurses asked me how do I think I contracted it, and I remember the place that I was living at, you talking about not happy. I wasn’t even happy in my marriage. I was like, you know, I even told my wife I’m ready to separate, you know--you go your way and I’ll go mine. I just couldn’t take it. It was just a lot, a lot, a lot of stress. And I told [the nurse], I said, “I think it had to do with stress and where I was living.” I wasn’t happy where I was at. I was stressing a lot, even though I take some things with a grain of salt, but it affected me even though I’m trying not to let it affect me. So, I told her, “It had to do with stress. It was the stress.” And she told me, “You know what? You could be right. It could be the stress that caused your pancreas not to function the way it was supposed to.” (#13)

Participant #10 attributed the onset of his diabetes to not taking care of himself, but was confounded by his test results because he had stopped “abusing” himself as he had years before being diagnosed.

I was just abusing my body. I was drinking, and my eating habits were crazy. The thing is, my health was great. The tests from my doctors never came out bad.
When I cut back on all that drinking and stuff, that’s when I started all of this diabetes with my numbers not where they were supposed to be (#10).

Two participants attributed the onset of their diabetes to conditions for which they had no control; but, followed by saying that they were not eating properly.

I said [to my doctor], “Wooohh! How did I get diabetes?” Then he said, “Well, who got diabetes in your family?” And then I said, “My mother and my father.” He said, “Well you got it.” I said, “Huh? How could I get diabetes?” He said, “Well, you see, it runs through the family”… Then I thought, “Well, I was eating a lot of, you know, crazy food and all that…I know I was eating it. (#7)

The other participant initially attributed diabetes to the food industry.

I’m addicted to sugar. That sugar is the strongest addiction there is because [the food industry] puts it in the food. It’s in everything...What I got to do is take the tastes out of my mouth because I love sweet tasting stuff with sugars…It’s the sugar, I think, that gives us that addiction and makes us diabetic. Well, my system stopped working and that’s why I became diabetic, I guess. I stopped digesting sugar. I still eat sugary things. [I know] it won’t be digested, and here my sugar level stays up. (#12)

**Learning from Adverse Events.** After realizing they had T2DM, participants learned about living with diabetes. However, most of their learning came through their own experiences of adverse events or other crises experienced by loved ones who also had T2DM. For example,. Participant #4 experienced erectile dysfunction.

I was like, ”Oh no, not me! This can't be real”…[I watched a video after I was diagnosed, and the] husband was explaining how diabetes affects his sex life. I'm
like, "Aw, man." I had wondered in that area what’s been going on with me. You know, I was concerned. I mean--because of course you want to please a woman every time, and I feel that I wasn’t capable. So, that was devastating. And then, when the doctor [had me watch the video], I was like, “Well now I understand it better, you know, what’s going on.” (#4)

Two other participants experienced crises—one hyperglycemic, the other hypoglycemic. The first participant reported that he had not been addressing the signs that let him know that his body was not functioning properly.

This diabetes thing…I wasn’t taking it seriously…I was somewhere on a cruise. Then I went to Florida. And then I went to Vegas. But I felt something. I felt like my sugar was high and I didn’t have my medication. I ran out of what I had…I started feeling something was wrong, so I kept drinking a lot of water. And I’m still messing up. I’m having my drink. I’m partying on the boat. I’m doing my thing. Get off of that [boat], go to Florida and still hitting the little clubs. I’m having a good time partying, drinking. But I’m noticing everyday I’m drinking lots of water. As soon as I put the cup down it felt like I hadn’t had a water all day. So by the time I got to Las Vegas, I was in [a store] and I thought, “If I take one more step I’m going to die.” I hit the ground. I sit right there. I got some help. Somebody ran over there, and I told them I was diabetic. “I don’t feel good. I feel like I’m going to die.” The pharmacist came over there. I was trying to explain stuff to her. [She] ran back in the back and stuck me with something, and said, “Here, take this.” I took what she gave me. They gave me a chair. I sat right there in that same spot for another hour maybe. I started feeling better. And then she told me she had
Because I was switching insurances, and I didn’t have it that day, it cost me $280 or something for a few pills. I said, “Give it here.” I needed them. [Before that], my sugar stayed at 2-, 3-, 400s…After that, I was more conscious of it (#12).

The second participant was taken completely off-guard, but said that he knew that he was experiencing hypoglycemia when the symptoms came.

I remember one time I was [at my sister’s house] painting and stuff… that’s when I knew how [to tell that] my sugar was low… I [felt] so nauseated, you know, and it’s like I just couldn’t focus. Everything was just confusing and I knew it was low. I knew it wasn’t high because when it’s high…I act normal… When my sugar gets high, it has no effect on me… I knew it was low because, like I said ….it was just different. I was just ill, that sick feeling, you know. As soon as I went and got a honey bun and some orange juice…It got me back right [to normal]. I say within 15 minutes, I was okay. I said, “Oh, Lord. I don’t never want to feel like that again.”… I couldn’t breathe, you know. It was scaring my son… My sister got scared, you know…She had her husband call me [later]. He was like, “You all right?” I said, “Oh yeah, I’m fine now”… So, I never really had that many episodes where my sugar got low. It was one time I was driving and I could feel it getting low. So, I always keep like peppermint and stuff like that, so I popped a mint in, and it shot right back up to where I was supposed to be.” (#13)

Participants also described experiencing adverse events by proxy.

One participant had a brother who—despite his intelligence, high level of education, and upwardly mobile career--ultimately died due to complications with the condition.
My brother…was taking the insulin…and he had other medicines that he would have to balance up or down. He used to take his blood levels--when he felt like it. He was not as compliant as doctors wanted him to be, very headstrong…He drank alcohol quite a bit, heavily I would say… His blood sugars were way out of whack. They would be as low as 60s – it even went down to the 20s one time. The next thing I know, another time a few months later, it was 1200…My brother who was highly intelligent, you know, the salutatorian from his graduating class, college-trained, you know, very, very high IQ… I was trying to get some help for him at home, trying to get some counseling. We were going to try to do that. Of course, he said he didn’t need it. But he stopped drinking for a while, which was good, but then he had a trigger that started him up again. And like a week later, he was gone. He was just sitting down watching TV, and he just sat right there and just died. He had the glass of alcohol right there next to him… I blamed myself for a while for not being there at the time, but I talked with him that night right before he died, so that was a comfort. So, it’s things like that that make you want to take care of yourself better, too. (#9)

In addition to learning from his own hyperglycemic crisis, Participant #12 described learning about the relationship between uncontrolled diabetes and impaired wound healing from his friend’s experience.

It was a couple of years ago when [my friend] had stepped on the nail. The bottom of his foot was black. And he was sitting on his recliner chair when I walked in, and I seen this thing on the bottom of his foot. He didn’t know it was there…We talked about it. He got up and went to the doctor, checked it out. He
told me thank you, saved himself. Here it is two or three years later, [and] he has a big ole cut on his foot now. Big ole piece of meat hanging off like something sliced it and it’s just hanging, and it’s black. And I went off on him. “Go get your foot taken care of!”…He said, “It ain’t that serious. I don’t feel it”…So, I talked him into going to the hospital, and he went—but, it wasn’t in time. So they cut half of his foot. A month later, they had to cut the other half of his foot. Weeks later, they had to cut him below the knee. Now they just cut him above the knee. And he don’t want to live no more…I had a scar on my leg…and it could have went the same way (#12).

**Figuring it Out.** The participants were motivated by these adverse events to figure out strategies to avoid experiencing them again. Some of these strategies included not owning, outright denying, or disassociating from the condition. For example, Participant #13 said, “You know they say if you mind, it matters. So, in my mind, I don’t never say I have diabetes. I’m always telling myself we’re going to heal this. You know, we going to heal this.” Similarly, Participant #6 stated, “[With] exercise and diet, I'm hoping and praying that that will take care of it…When I pray, I don’t say I’m diabetic. I don’t accept that about me.” Participant #2 calls diabetes “nonsense”. She disassociated who she was from the condition.

In contrast, Participant #1 said that he was in denial when he was first diagnosed, but finally surrendered to it. “I was living with my mother. I was drinking…not knowing that the effects would come later, you know. And, I got diagnosed with diabetes. ‘I ain’t got no diabetes.’ Yeah, but I had it.”
Figuring it out also entailed narratives about using trial-and-error to self-manage the condition. Participants would utilize multiple strategies to see what worked.

I was managing, but I wasn’t doing it the right way. Sometimes, I would jump off the ledge and start messing around like eating a lot of sweets and stuff like that, you know…. When I seen my blood sugar get up like over 160 or something like that, or get up to 200, I know that I’m doing something wrong and I would back off, you know…stop eating sweets and stuff like that. And I would drink diet sodas, you know. I was told that sometimes, some of the diet sodas are no good.

I didn’t know that. So, I just started drinking water…But, then, I had a little chart that I would take to monitor my blood sugar and stuff like that, and I would do that and…the nurse would call me and I would give her the readings. She would call me once a week…to get a reading… to monitor my diabetes, you know. So, when I got on the insulin, you know, she stopped [calling]. (#1)

One participant described working with his doctor to initiate trial-and-error strategies.

The doctor I have now, he’s good…because we talk. When I go, he do what he have to do and he just say, “Okay, anything you need to ask me?… Is there something new I need to know?”, or something like that…But, once he do the A1C and all that, he go, “Ooooh. You know, you kind of up. So, I don’t really want to put you on insulin”-- the real insulin, because I do [a long-acting insulin]—“because I don’t want you going there yet. We’re going to try to control it with this.” So, he gives me an opportunity to work things out….He was telling me like, “You know, I know it’s the holidays. I know we got those bad eating habits and
stuff, so I’m kind of expecting it to be off. But, I’m going to give you [only] so much time so we can get it together and get it down. (#13)

Another trial-and-error strategy that was employed was when a participant adjusted his diabetes medication on his own when he thought that it wasn’t working.

When I first started, I wasn’t taking it right. I was only supposed to take one [pill], three times a day. And I’m like, “Why am I taking this? I'm not feeling no different. Nothing's going on.” And then, actually, I don't know why I took two - probably because I missed one. It was like, I started feeling a difference… So, I took two pills, two-to-three times per day… I'm asthmatic. So I take medicines for that, and there were times that they experiment on you. “Try this, try this, try that.” There were a lot of things that wouldn't work. Then I read where it said that a lot of the medications are like that. And that's why I basically started doubling up on [my diabetes pills]. Then I found out that wasn’t what I supposed to do (#4).

Participant #9 made adjustments to her food.

I try not to deny myself of foods that I really want to eat. But, I know if I’m eating something bad, I'll know the next day or the rest of the day, or next couple of days, don’t eat like that and try to keep it even (#9).

Two participants figured out that successfully self-managing diabetes was relatively an insurmountable feat due to their psychosocial barriers. One participant stated that she continues to feel disempowered by the condition. “I do what I can to get the right foods to eat, but I can’t always afford what I need on my income. Next thing you know, I’m just eating whatever I want, and not caring about the consequences” (#14). Another participant reported that she has become anxious and worried. “I think,
‘What if I go to sleep and don’t wake up because of this diabetes?’ I live by myself. One minute it’s high, the next minute it’s low. Makes me nervous about sleeping at night” (#3).

**Being Mindful of Age-Related Realities.** While figuring out strategies to manage diabetes within the context of their lives, participants described needing to be mindful of their own mortality and their own physical function risks because of their age. So, as they made sense of diabetes, they described being aware that they are older now, and being more aware of what could happen to them because of their advanced age. For example, Participant #12 said, “I love food. But I gotta change some of this stuff…change my way of life so I can see 80… healthy and not in a wheelchair. Not losing my legs. I don’t want to really be around like that.” Similarly, another participant noted the need to take care of herself in older age.

Sometimes I get some [foods that aren’t good for my diabetes] and I eat it, and then I just say, “You know you don’t supposed to eat that. Let that stuff go. You know it’s bad on your health.” I can’t eat it like that no more because I’m older. I’m 56 years old (#7).

Two other participants stated that older adults need to limit sweets as they age.

I think that the older you get, you just got to let [the sweets] alone. Every now and then, you might can treat yourself, maybe a birthday cake or something like that. Eat a little piece of cake and that’s it. Let it alone. Don’t go back and start dipping too much, you know. But, it’s hard (#1).
Despite the difficulty in having to limit sweets, the other participant stated that it came down to making the choice to not eat sweets in excess.

There comes a time when you’ve just got to choose what you’re going to do. With the time that I have left on this earth, I want to make sure that I have all my limbs, that I’m not blind”…So, I tell myself, “Have a cookie, but don’t go crazy (#5).

Taking Control

In taking control, participants’ ascriptions included a mix of having some level of understanding about what they needed to do to manage diabetes without complications, and giving themselves permission to indulge in “bad” foods on occasion. When those occasions arose, participants reported that they implement strategies to bring their bodies back to their norm. Additionally, incidences of taking control of diabetes was directed by the signs and symptoms that they experienced (e.g., pain, feeling “off”), and not necessarily directed by standard medical indicators of T2DM (e.g., elevated or low blood glucose level).

Doing What’s “Right”. To take control, participants described having to do what was “right” to self-manage the condition.

I know I got to do what’s right…. What’s right is I know I got to eat right. I know I got to exercise, you know. I got to do what’s right if I want to be around. You know, I got grandkids. I love my grandkids (#13).

Another participant described doing what’s right as going to her doctor regularly and engaging in the treatment decision-making.

I go to the doctor at least every 3 months, you know, to make sure I’m being followed. My doctor knows me very well, so she knows the dosages, if they’re
working or if they’re not, she’s makes adjustments if necessary. She explains a lot to me and she likes my input as well. She’s not one to say, “Oh, you must do this or you must do that.” She’ll say, “Okay, here’s the choices. We can do this or we can try this or that.” And she’ll, more or less, leave it up to me to help with the decision. So, I feel like I’m more vested in it, more apt to follow it if I’m part of the decision. That’s basically it (#9).

One participant described doing what’s right in terms of righting bad food choices.

Yesterday after church, my kids took me to dinner…I did fall off the wagon…Yes, Lord. The meals that we got came with ice cream something, but I didn’t want that. They had that cream cheese—the cheesecake. I fell all the way off the wagon. I fell under the wagon…But then when I got home, I drank a lot of water…With diabetes I have to start drinking a lot of water… The water helps…It will run you to the bathroom to flush it out (#8).

Two participants described doing what’s right as simply taking their diabetes medications. “There is nothing better that I can do than take my [diabetes pills]. I make sure that I take it every day” (#10). The other participant stated, “I’m taking insulin everyday… I don’t take [my blood sugar] every day, though. I really don’t know why. I’m thinking if I take my insulin, I’ll be alright” (#1).

In contrast, Participant #2 stopped taking her medication altogether, and opted for an over-the-counter supplement to do what she thinks is right to manage her diabetes.
When I was in the [diabetes] program… right at [the clinic]… they give me a card that I go there to measure this, that and the other. And every month when I go there, they test my blood--and this is the reason why I stop take them pills. Every time you go there, it’s the same reading for five years?... I bring it up. I say, “Why is it that every time, every month I come here, and dutifully I take it to be my business to prove what I want to prove. I take those pills according to how they are being prescribed. I am not a, what you call, an oil eater, period. I am not a sugar drinker, period… Salt, we do not cook with salt, period. So, hey! Why is it that every time I come here, my blood [sugar] is 350, 250. What is the matter? And I am one person that God made, I will question. And up to today, they have never tell me what was the matter. Never! So, two years ago… I did not go to clinic [any longer]… Two years ago, I stopped take medication from [clinic]. What I did, I went to [the drug store] and buy an over-the-counter medicine, the capsules for diabetes... It’s a supplement.

Participant #7 reported that she had never been recommended for a diabetes self-management class, and that her doctor had given her little instruction on how to improve or manage the condition. So, she followed the advice given by her family.

I used to be bigger than this, but I done came down some…I just learned just to push back from that table and leave all that fried food alone…My sister and them kept telling me to quit eating a lot, quit doing this, and quit eating this, quit eating that, so I just stopped doing it. In my freezer, I got food in there. I ain't fried no fried food, I ain’t frying nothing. I just been boiling my food … and baking it, and
eating a lot of vegetables, salads and that’s it. So I’ve been cutting back a whole lot.

**Using Diabetes Symptoms as a Guide.** The second means of taking control that participants described was using their symptoms as a guide. They trusted that their bodies were going to tell them what they needed to do to take control of their diabetes. “If I’m feeling good, then everything is okay. You know what I mean? Now, if I am not feeling good, then I attend to it” (#10).

Another participant described using pain as an indicator. “My sugar goes down to the 60s at times…But, I don’t have any pain when it’s that low” (#3). Despite standard medical recommendations regarding keeping one’s blood sugar above 70mg/dL, this participant waited for her body to experience pain before she deemed it as harmful. Similarly, another participant noted that she checks her levels from time-to-time; but, she remained watchful for symptoms when she was feeling off. “I do check [my sugar] on my own periodically…[But,] I look out for the signs of, you know, my sugar being high, can’t really concentrate, headaches, you know, when I just don’t feel right” (#9).

**Summary**

In summary, participants described diabetes as something that was scary, insidious, had the power to overtake and change individuals’ lives. In their efforts to not be changed by it in a deleterious way, participants tried to make sense of the condition and learn to live it.

Learning to live with diabetes included finding out the root cause of its presence in their lives. Many participants’ learning was internalized by obtaining experiential understanding by encountering adverse events—personally, or by proxy. Having
exposures to what could go wrong, participants tried various strategies to figure out what might work for them. Finally, making sense of diabetes included having a heightened awareness about their advanced age, and their desires to continue to age with their eyesight and limbs intact.

Once participants had a handle on what diabetes was and how it could affect them, they sought to take control of it by doing what was “right”—i.e., following self-directed rules and strategies that appeared to work in their lives. Additionally, participants described being aware of their bodies and trusting that their bodies would give them signs when something was not right.

**Grounded Theory**

The culminating aim of this study was to generate a theory grounded in the narratives of the participants that explained the relationship between lifetime experiences with structural racism and uncontrolled diabetes in older age. The participants were not directly asked to identify the relationship between lifetime experiences with structural racism and uncontrolled diabetes in older age. They were given an opportunity to talk about it, but none of them did. The author’s interpretation of the fit of the relationship, however, follows in Chapter 6.
Chapter 6

DISCUSSION

Summary of Findings

The first aim of this study was to describe structural racism-related experiences among older African Americans. Major categories identified were Being separate, Facing threats, Experiencing injustice, and Protecting personhood. The findings revealed the context within which the participants lived, went to school, worked, raised their families and aged. This context included being separated from Whites, and having inequitably different and limited resources and opportunities to enrich their lives.

The second aim focused on identifying meanings about the structural racism-related experiences in the first aim. Major categories included Being outsiders, Needing to level the playing field and Needing to take care of self. Findings also highlighted the processes and strategies that participants used to navigate their social context in a more equitable way. They did this by identifying power structures that treated participants as outsiders who were relegated to the lowest rung of the race-based social hierarchy. They employed strategies where they consciously maintained a heightened awareness when it came to Whites—being mindful of their intentions, actions, and hidden ideologies. They also joined together with others in their communities to strengthen their power and to compensate for one another’s deficits.

As they learned to better navigate structural adversity, participants awakened to their own self-power. They continued to build and stand on a sense of independence by taking responsibility for themselves and their loved ones. They also spoke up and took action against injustice, and positioned themselves for better social options than were
structured for them within their communities. They also learned to trust themselves as they refused to succumb to the limitations imposed by others.

The third aim sought to describe participants' experiences with diabetes. Participants described their experiences when diagnosed and their experiences with surviving with diabetes. Major categories included Fearful anticipation, Learning to live with it, and Taking control. Each person described diabetes as something to fear to some degree. Participants were afraid that they were about to die, worried that they would lose a limb, concerned about being able to manage the illness, and they expressed feeling “depressed” because they felt like they had been changed.

Despite being afraid and feeling changed in response to hearing that they had diabetes, participants described a process of learning to live with diabetes within the context of their lives. They sought to understand how they obtained it, had a heightened awareness about adverse events experienced by themselves and others within their social networks, and described trying a variety of strategies to discover what worked for them. Participants also described being aware of the risks of having uncontrolled diabetes as an older person.

Taking control was the final process that emerged among participants' ascriptions about diabetes. Strategies to take control included following a set of self-prescribed rules such as drinking a lot of water after making “bad” food choices, or balancing “bad” food choices with making “good” choices for a couple of days afterwards. Taking control also included listening to their bodies, and using how they felt as a guide for self-management.
The final aim of the study was to generate a theory that was grounded in the voices of the participants that explained the relationship between lifetime experiences with structural racism and uncontrolled diabetes in older age. Participants did not state there was a relationship, despite being given the opportunity to do so. However, I drew upon the participants’ narratives to offer my interpretation of the relationships between structural racism experienced throughout the life course, and diabetes-related experiences in older age among this sample of 15 participants.

Learning and Playing the Game

My interpretation of the fit between participants’ narratives about structural racism and diabetes was centered on the processes through which participants dealt with social- and health-related threats. The processes were revealed in the major categories and sub-categories that were presented in Chapter 5. The categories clustered into three major constructs: Identifying Threats, Learning and Playing the Game, and Exercising Agency (Table 5).

Major Constructs

The first major construct was Identifying Threats. Although the threats differed in participants’ narratives about structural racism and diabetes -- i.e., they were human threats as it related to structural racism, and disease-related threats as it related to diabetes -- participants perceived risks or harm to themselves. Participants described being socially diminished on the race-based hierarchy, and feeling diminished and broken with diabetes. Additionally, parallels can be drawn between the lack of control that participants described having over themselves in the structural racism context, as they faced threats and intimidation, and the lack of power and control that participants
described having when they initially felt overpowered and changed by diabetes. In regards to the feelings of hopelessness that participants described, a parallel can be drawn between the figurative loss of vision with the assassination of Dr. King, and the literal loss of sight that one participant had begun to experience as a complication of diabetes. In both cases, the participants felt a notable sense of loss.

The second major construct was an interactive process of “Learning and Playing the Game” in which participants assessed and engaged in structural racism- and diabetes-related situations. Parallels between participants’ structural racism- and diabetes-related narratives can also be drawn in the second construct, “Learning and Playing the Game”. Both processes (the process that participants described related to structural racism, and the process that they described related to diabetes) involved learning through personal experiences and through the experiences of others. Both processes caused participants to have a heightened awareness of overt and insidious threats that they perceived. Both processes also entailed joining with others as a means to living with their respective social and health conditions.

Interestingly, as indicated in Table 5, the Learning and Playing the Game construct ended with a transformative awareness of self as it related to both the structural racism- and diabetes-related categories. “Awakening to Self-Power” was a game-changer in that it was an evolutionary process that evolved out of Learning and Playing the Game, into Exercising Agency. Participants discovered that they had the capacity to be autonomous and to act on behalf of themselves. Similarly, “Being Mindful of Age-Related Mortality and Physical Function Decline” was an overlapping process
that evolved out of “Learning to Live with [Diabetes] and “Taking Control” of the condition in ways that made sense to participants.

The third major construct was Exercising Agency. Parallels can be drawn between the language of “Needing to Take Care” and “Taking Control” of one’s self. This interpretation is not suggesting that the ways in which participants chose to take action on behalf of themselves were “right” or “wrong” – it’s describing the parallels that were evident to me in how they chose to take ownership of themselves and to do what they thought was useful and worked for them.

Table 5. Thematic Patterns between Participants’ Structural Racism- and Diabetes-Related Narratives

<table>
<thead>
<tr>
<th></th>
<th>Identifying Threats</th>
<th>Learning &amp; Playing the Game</th>
<th>Exercising Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SA1.</strong></td>
<td>Facing Threats</td>
<td>Experiencing Injustice</td>
<td>Protecting Personhood</td>
</tr>
<tr>
<td></td>
<td>- Being Warned to Stay Away</td>
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<tr>
<td></td>
<td>- Dealing with Intimidation</td>
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<tr>
<td></td>
<td>Being Outsiders</td>
<td>Needing to Level the Playing Field</td>
<td>Needing to Take Care of Self</td>
</tr>
<tr>
<td></td>
<td>- Having Less Social Value</td>
<td>- Being Watchful</td>
<td>- *Awakening to Self-Power</td>
</tr>
<tr>
<td></td>
<td>- Losing Hope</td>
<td>- Joining Resources</td>
<td>- Being Independent</td>
</tr>
<tr>
<td></td>
<td>- Being Mishandled</td>
<td>- *Awakening to Self-Power</td>
<td>- Taking Action</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>- Taking Ownership</td>
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<tr>
<td><strong>SA2.</strong></td>
<td>Fearful Anticipation</td>
<td>Learning to Live with It</td>
<td>Taking Control</td>
</tr>
<tr>
<td></td>
<td>- Fearing the Unknown</td>
<td>- Attributing a Cause</td>
<td>- *Being Mindful of Age-Related Mortality and Physical Function Decline</td>
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<tr>
<td></td>
<td>- Feeling Overpowered</td>
<td>- Experiencing Adverse Events</td>
<td>- Doing What’s “Right”</td>
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<td></td>
<td>- Feeling Changed</td>
<td>- Figuring it Out</td>
<td>- Using Symptoms as a Guide</td>
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<td></td>
<td></td>
<td>- *Being Mindful of Age-Related Mortality and Physical Function Decline</td>
<td></td>
</tr>
</tbody>
</table>

*Denotes overlap into more than one construct

Lastly, each of the structural racism- and diabetes-related patterns co-occurred, particularly during the later years of participants’ life courses. Although unstated by participants, the structural racism- and diabetes-related processes that they described
experiencing appear to be embedded in a life trajectory that had been continually surrounded by a structurally-limiting social context.

**Core Construct**

The core construct of my interpretation was drawn from participants' experiences with structural racism. I identified it as Learning and Playing the Game, which is a basic process of self-empowerment in which African American seniors in this sample took control of themselves in life-threatening or life-limiting conditions. This process operated within the context of structural racism, operated continually over the participants’ lifetime, and had influence on their ways of being and behaving.

The terms “learning” and “playing” “the game” were in vivo codes used to describe the structural racism-related context that surrounded life for members of the sample. The “game” was defined as the manipulation of power to empower and advantage one’s self or racial group, and to “other” those who are outside of one’s racial group in order to achieve or maintain a high social ranking. Participants perceived the game as created by Whites, and in their aim to maintain their social advantages, Whites disadvantaged Blacks and their communities. In order to protect themselves against being taken advantage of or overpowered by the insidious and overt acts of Whites, AAOA’s in this sample described how they learned to play “the game” by being watchful of those who opposed or oppressed them within their communities, and by joining resources with other community members in order to help meet one another’s needs for survival.

The process of “learning the game” was defined, first, as understanding that there were power differentials at play. The participants realized they had less power
than Whites in their communities. Second, in order to gain power, participants explained that they learned it was important to stay vigilant in guarding themselves against oppressive actions against them, whether overt or hidden, and to compensate for their deficits by joining with others. Ways to learn the game included listening to what others said, watching what they did, questioning their intent, and practicing strategies that were perceived as useful to the individual. Participants described that learning to play the game could occur via direct or vicarious experiences.

One aspect of “Playing the game” was defined as taking ownership. “Playing” began with self-awareness. This occurred when the participant recognized that they possessed an internal strength and resolve that could empower them to take control of themselves and their personal circumstances despite the conditions that surrounded them. Among the ways to play the game were defining one’s self, gathering one’s own resources, speaking up and taking action out of duty to one’s self or others. For some, playing the game was rooted in their sense of self-control and autonomy; playing could be enacted individually or in collaboration with friends or partners.

I saw “learning” and “playing” the game” as one construct because they were non-linear activities where one led to the other (Figure 5). As participants were exposed to an experience or phenomenon and gained an understanding about what it was and how it worked by watching, listening, and making sense of it through their own interactions, or vicariously through the experiences of others, they began to discover what worked for them, and gained a sense of control over their own choices and behaviors.
Learning and Playing the Game: Dealing with Structural Racism

For this sample of 15 AAOAs, the process of learning and playing the game was influenced by “identifying threats” in the form of structural racism and had the outcome of “exercising agency” (Figure 5). Threats included people with authority or power due to their resources or their racialized identities, and who posed immediate or perceived risks or harm. As an outcome of negotiating these risks and inequitable experiences over time, the participants learned to exercise agency in an attempt to stand in one’s selfhood, or to protect the personhood of others. They spoke up, took action and claimed ownership by providing for themselves in the face of structural racism.

Figure 5. Learning and Playing the Game
Learning to Live with Diabetes

Diabetes was perceived as a threat to the health and well-being of the participants. Learning to deal with the threat included understanding the dangers that were being faced, and learning to negotiate those threats without the condition limiting their lives (e.g., due to amputations, vision loss, or diabetes-related death). Diabetes self-management was self-powered for this sample. It included defining one’s own self-management rules in partnership with trusted others, and controlling one’s own behaviors if those rules were broken. Playing the game of diabetes self-management also included taking ownership of one’s body (e.g., trusting that the body would help them to avoid diabetes-related limitations), and taking ownership of one’s choice to live successfully with the condition (e.g., for the sake of being alive and well for grandchildren).

Summary. In summary, Figure 5 is fueled by Figure 3 and represents the relationship between the strategies that this study’s sample used to negotiate social threats in their lives related to structural racism. Despite occurring largely at different stages in their life course development, these experiences led the participants through a process of identifying threats to their lives, learning and applying strategies so as not to be overpowered by them, and taking ownership of themselves despite the structurally-limiting context that surrounded them. Figure 4 provides a diagram of the key elements of this sample’s process of dealing with T2DM.
Linkage to Structural Racism Literature

Findings of this study revealed a number of important understandings about structural racism, particularly in the context of the life course. Researchers have identified several characteristics of structural racism that distinguish it from other forms of racism (Bonilla-Silva, 1997; Gee & Ford, 2011; Jones, 2000; Powell, 2007; Williams, 1997). First, there is no clear actor, yet inequitable outcomes persist. The structure gives rise to the conditions that are necessary for its persistence over time, including the labeling of different racial groups, and the differential distribution of resources, rewards and punishments along racial lines (Bonilla-Silva; Link & Phelan, 1995).

Participants frequently described the persisting condition of having no jobs, programs for youth, and resources such as public libraries and major chain grocery stores in their communities. Additionally, participants described being over-policed and unjustly treated in the criminal justice system. They did not identify “who” might provide the jobs, programs and resources; however, being under-resourced coupled with the persisting condition of being unfairly targeted and brutalized by police angered the community, and triggered the Watts Riots and Rodney King Riots in 1965 and 1992, respectively. The emotional consequences of injustice persisted in older age as well. Participants described being angered and experiencing pain following the recent murders of young, Black males and females by White civilians and police officers. They noted that the lack of subsequent convictions for those attacks further affirm that laws are unequally applied between Blacks and Whites.

In terms of participants’ persisting socioeconomic condition, a connection can be drawn between participants’ ascriptions about being perpetually under-resourced and
the demographic data that they self-reported. Among the participants who provided their annual income, most reported that they receive less than $30,000 per year. In addition, only one participant described having a professional career; others described having jobs in maintenance, as janitors, and working multiple jobs simultaneously in order to take care of their needs, and to provide for things that they wanted. One participant shared that her lack of financial resources was a barrier to her diabetes self-management, and has frustrated her to the point of giving up on trying to self-manage the condition at times. These participants' experiences demonstrated the socio-economic impact of structural racism’s persistence over time.

Researchers have noted that structural racism also shapes the interactions between individuals and institutions over time, which generate and reinforce inequitable outcomes (Bonilla-Silva; Powell). Bonilla-Silva associated these outcomes with individuals’ life chances, and noted that Blacks’ life chances are significantly lower than those of Whites due to the racialized social order in the U.S.

Participants’ ascriptions about interactions with teachers and counselors in high school echoed existing literature. One participant described his teacher making jokes when he asked questions, and other teachers not taking his desire to learn seriously. When he transferred to a predominantly White school, he described being drastically behind and noted the stark differences in the quality of education between the predominantly White and predominantly Black high schools. Another participant stated that it was of no significance to her teachers and guidance counselor when she dropped out of school six months before graduation. She said that she was just one less person on their rosters. Another participant noted that his guidance counselors supported him
and his football team by attending their games, but never supported their academic and professional achievement by directing them towards college. The educational system is an institutional domain that directs the trajectory of students into adulthood. The interactions with, and the guidance offered by teachers and counselors directly influence students’ employment, housing, and socioeconomic mobility opportunities (Bonilla-Silva, 1997; Powell, 2007).

Structural racism is additionally distinguished by its invisible, “taken-for-grantedness”. Gee and Ford (2011) described it as undetectable and difficult to eliminate because it is deeply embedded in our country’s social organization. Powell (2007) explained that once structures have been established, they have a logic and momentum that replicates and naturalizes meanings that the structures help to shape. Similarly, Bonilla-Silva (1997, p. 474) described the ideological component of structural racism as crystallizing racial notions and stereotypes, noting that the ideologies become “common sense”, and provide the rules for perceiving and interacting with the “other”.

Likewise, participants in this study described the hidden nature of racism and the sense of “being outsiders” who were stigmatized and misrepresented within multiple domains of society. They noted that racism hid in the system, and that it was not easily identified because it was always changing. They described the veiled nature of racism manifesting as an ideology that they termed “white sheets,” and described their continued need to be aware of its presence in their day-to-day interactions.

Another distinguishing characteristic of structural racism is its contribution to identity formation through the hierarchical arrangement of racial groups, and the struggle that occurs between races to either maintain or transform the racial order.
(Bonilla-Silva, 1997). Powell (2007, p. 811) stated: “The structures that we inhabit not only distribute material benefits and burdens across society, but also distribute meaning, which in turn shapes racial attitudes and influences the formation of racial identities.”

Participants described being perceived by Whites to be inferior, coming to know for themselves that they were part of a marginalized racial group with limited resources and little social power, and consequently stretching themselves beyond what was expected in order to prove that they mattered and had value. The findings from this study match with the literature in regards to the race-based threats and intimidation that participants described experiencing, and the need that they described to level the playing field to challenge the social order.

Interestingly, the participant who migrated to the U.S. from a Caribbean country during middle adulthood was less affected by that social perception of Blacks. As a dark-skinned woman she identified as Black, but noted that she did not belong to this country. Bonilla-Silva (1997) noted that historically, dark-skinned immigrants from Africa, Latin America and the Caribbean struggled to avoid taking on a “Black” identity due to Blacks in America being relegated to a subordinate social status.

A unique contribution of this study was its focus on the meaning of structural racism to individuals and how structural racism influenced their behaviors and strategies for navigating social threats. This study deepens our understanding of the individual level self-management strategies that have been employed in response to, and despite, living within an environment that was structurally designed to limit, other, and maintain older African Americans’ low social position due to their race. This study revealed the
perspective of self-empowered individuals, as opposed to the view that structural factors impose overwhelming power in these individuals’ lives.

**Linkage to Existing Literature on Structural Racism and Health**

Existing literature has provided a solid foundation that defines, characterizes, and provides connections between factors that link structural racism and population health (Bonilla-Silva, 1996; Gee & Ford, 2011; Jones, 2000; Powell, 2007; Smedley et al., 2003; Williams, 1997). The landscape is growing as researchers in the fields of public health and sociology, in particular, increasingly identify structural racism as a fundamental cause of disease and health inequity among racial/ethnic populations (Ford & Airhihenbuwa, 2010a; Link & Phelan, 1995). Their work has revealed multiple layers of structural inequity, particularly in the distribution of resources to racially-isolated communities and its negative effects on population health among racial/ethnic groups (Gee & Ford).

This study provides insight into this sample’s experiences of structural racism as individuals. The nuanced interpretation that this study offers is based on individual-level accounts, experiences, and life trajectories that in the context of structural racism within which the sample has lived throughout their lives. This study deepens our understanding of structural racism in the lives of participants, who each had uncontrolled diabetes. This study narrows the scope of structural racism as it examines its relationship to individual-level health behaviors. It shifts the lens from the ways in which structural racism limits and disadvantages individuals, to the perspective of the individuals, who have learned to push back against structural limitations.
Structural racism has indeed victimized African Americans (Smedley et al., 2002). However, by focusing solely on the barriers that it continues to impose upon this group, we miss the strength and actions of the “victims” who have survived despite ideological threats and limitations. From a nursing perspective, this study provides insight into this sample’s experiences of structural racism as individuals. The nuanced interpretation that this study offers is based on individual-level accounts, experiences, and life trajectories that in the context of structural racism within which the sample has lived throughout their lives. This study deepens our understanding of structural racism in the lives of participants, who each had uncontrolled diabetes.

**Linkage to Existing Literature on Diabetes Self-Management among Older African Americans**

This study contributes a novel perspective on the approaches to diabetes self-management that African American older adults with uncontrolled diabetes employ. This study deepens our understanding about the self-driven motivations that undergird AAOA’s efforts to survive with T2DM, making it a study unlike most others in the diabetes self-management literature. Most studies have sought to associate African American seniors’ uncontrolled diabetes and excessive rates of complications to their health literacy (McCleary-Jones, 2011), problem-solving abilities and self-efficacy (Amoako et al., 2008; Bhattacharya, 2012; Fitzpatrick, Schumann, & Hill-Briggs, 2013; Hill-Briggs, Cooper, Loman, et al., 2003), standard self-management education and behaviors (Gitline et al., 2008)—including dietary choices and habits (Auslander, Haire-Joshu, Houston, Rhee & Williams, 2002; Brewer-Lowry, Arcury, Bell, & Quandt., 2010; Sumlin & Garcia, 2012), penchant for exercise (Agurs-
Collins et al., 1997), and spirituality and fatalistic beliefs (Polzer & Miles, 2005; Samuel-Hodge et al., 2006; Samuel-Hodge et al., 2009).

One study in the literature rooted African Americans’ patterns of understanding diabetes and diabetes self-management within a multigenerational context. Findings from the study revealed that participants gained an understanding about diabetes through the illness representations, controllability beliefs, and diabetes-related complications of family members (Scollan-Koliopoulos, O’Connell, & Walker, 2007). As a result, the study’s participants largely experienced similar behavioral outcomes and perceptions of controllability as family members whose experiences were negative.

The current study revealed a similar pattern of our sample gaining understanding by proxy. However, our sample demonstrated that their exposures to adverse events increased their motivation to avoid experiencing those complications personally, if experienced by proxy, or having a repeat event if it was experienced for themselves. Our sample described a commitment to learning ways to avoid diabetes-related complications in their own lives.

This study’s findings revealed older African Americans’ self-empowered approaches to diabetes self-management that were similar to the strategies that our sample described employing across the life course when taking control of themselves within a structurally-disadvantaged environment. This perspective has been extraordinarily understated in the literature. As a result, this study has provided a jumping-off point for future research to explore AAOAs’ views of the influence of structural racism on their personal health-related trajectory, including their T2DM self-management strategies.
Linkage to Theory

Life Course Perspective

The life course perspective undergirded my study of the relationship between early life experiences with structural racism and later life experiences with diabetes. Life course is a theoretical orientation that has been utilized across disciplines in various ways to study population health and aging (Alwin, 2012; Elder et al., 2003). Alwin conducted a multidisciplinary literature review on the term “life course” and identified five conceptual uses of the term. The use of “life course as early life influences on later adult outcomes” (p. 213) was most salient to this study. Kuh, Ben-Shlomo, Lynch, Hallqvist and Power (2003) explained that this use of life course links socially patterned exposures during childhood, adolescence, and early adult life, to health and disease risks in later adulthood. It also links socially patterned exposures to behaviors in later life. Of particular relevance to this study is self-management behaviors.

This study utilized a bottom-up approach that led to identifying thematic patterns of behavior that were driven by structural racism-related exposures in early life. For example, when participants recognized threats to their lives in their early years through interactions with the police, educators, and businesses, participants described being watchful, and having a heightened awareness about the motivations and actions of those who participants perceived to have ill-intentions towards them. In addition, participants described joining together with their friends and community to help meet one another’s needs for survival—e.g., when confronted with physical aggression, and in meeting their basic food needs. Acquiring the knowledge and skills to engage in “game play” occurred over time as participants matured into young adulthood.
Similarly, when participants recognized diabetes as a threat to their lives in their later years, they watched other people’s adverse experiences with condition, and gained a heightened awareness about their own acute responses to the condition when they were dangerously out of control. They described partnering with their nurses and doctors to understand the condition and how best to manage it within the context of their own lives. Participants also described developing strategies that they believed worked best for them. Although the strategies were not always based on standard medical recommendations, and although participants described being inconsistent in the application of their strategies, they aimed to figure out ways to preserve their life, limbs and eyesight while living with this condition in older age.

To my knowledge, the findings that were derived from this use of the life course perspective are new. The congruency between the findings of this study and Kuh and colleague’s (2003) explanation of the relationship between socially-patterned exposures in early life and their relationship to health-related risks and self-care behaviors in older age advances the usefulness of the life course perspective in the study of uncontrolled diabetes among African American seniors.

Pragmatism

Pragmatism is grounded in the concept of usefulness—i.e., that individuals interpret their environment and act according to what they perceive works for them (Charon, 2010; Warms and Schroeder, 1999). These participants exercised agency in their efforts to manage their diabetes in ways that made sense to them within the social context and social conditions. They described being watchful, joining with others, and
taking control of themselves by doing what they felt was “right” socially and as it related to managing their diabetes day-to-day.

This study enhances our understanding of pragmatism within the context of the agency that African American seniors have exercised to survive within a structural racism-related environment and also about living daily life with their diabetes condition. Although the diabetes-related strategies were not always consistent with standard medical recommendations, participants described employing multiple tactics in search of what worked specifically for them.

**Limitations**

The discussion of the findings of this study have limitations. My discussion draws upon the life course perspective to link early-life experiences with structural racism and later-life experiences with diabetes. However, minimal data were collected that described the transitions and experiences that participants encountered during middle adulthood (e.g., marriage, divorce, widowhood, birth and loss of children, their children’s interactions with gangs or the criminal justice system, work and career trajectories) that may have strengthened or altered the interpretation of this study’s findings.

In addition, I acknowledged the influence of life development in an attempt to contextualize participants’ ability to derive meaning from their experiences during developmental stages throughout their lives. Although they were beyond the scope of this study, exploring psychological and psychosocial factors such as personality, motivation and lifespan development factors might have contributed an interesting addition to this study’s findings and expanded understandings about learning and playing the game.
Furthermore, the concept of agency was identified as an outcome of the experiences that participants have learned to negotiate throughout their lives. Agency is a multi-modal concept that can be exercised personally, collectively, and by proxy (Bandura, 2006). My discussion of the findings of this study has focused on the personal exercise of agency in participants’ approaches to taking control of self in both the social and diabetes-related contexts. A deeper look into how agency is exercised in other ways within a structural racism-related context might be useful.

Finally, this study is a situation specific study done with a small sample of 15 AAOAs. Thus, it cannot be assumed that the process of “learning and playing the game” is unique to African American seniors with uncontrolled diabetes. It is also not possible to assert a direct connection between success in controlling diabetes and structural racism.

**Nursing Research and Practice Implications**

This study established a foundation on which nurse researchers can build to explore the relationship between lifelong experiences with structural racism and an uncontrolled, but manageable chronic disease condition like T2DM in older age. Nursing interventions are needed that help empower persons from structurally-disadvantaged communities to successfully manage chronic conditions like diabetes. The findings from this sample, though small, indicate that African American seniors want to play an active role in the management of their health. They want to live well into older age with all of their physical and functional faculties intact. By understanding the complexities of their life histories and acknowledging the structural context that continues to surround their
lives, our research can support their goals of successful self-management and optimal health.

A significant practice implication revealed in this study is that although knowledge is not sufficient in controlling diabetes, it is necessary. It was a surprising finding that many of the seniors did not know what diabetes was at the time of diagnosis. Most were familiar to the extent of knowing someone who experienced a complication from it, or that it was a condition that people got within the Black community. Carper (1978) referred to this as esthetic meaning—i.e., understanding that is gleaned from subjective experience. However, participants were unfamiliar with what diabetes was, how it develops, and most importantly, how it can be successfully controlled without experiencing complications.

Nursing practice can be strengthened by these findings in terms of the education that is given to patients and communities about diabetes. More attention can be given to teaching patients about the condition and how to effectively self-manage it—not just in offering printed educational materials, but in talking about it with their patients and confirming their understanding within the context of what they may have already observed or experienced by proxy. This study’s findings have broad implications for the need to educate communities about the disease and its meanings in the lives of Black Americans as well.

**Future Research**

Future nursing research needs to compare ascriptions made by African American seniors with uncontrolled diabetes and the ascriptions of seniors whose diabetes is considered controlled. This might lead to nuanced findings that reveal meaningful points
of intervention. It would also help clarify the causal connection between early life-time exposures and self-management behaviors in later life.

Additionally, given that nursing practice and research are grounded in the study of individuals from pre-conception through death, future research is needed that focuses specifically on the structural racism-related experiences that have occurred during specific developmental stages throughout the lives of African Americans. This would help elucidate relevant connections between early life experiences and later life self-management of diabetes.

Future research also needs to consider the transitions and experiences that participants encountered during middle adulthood (e.g., marriage, divorce, widowhood, birth and loss of children, their children’s interactions with gangs or the criminal justice system, work and career trajectories) and how these impact self-management in later life. In addition, consideration should be given to the influence of psychological and psychosocial factors such as personality, and motivation as they impact self-care behaviors among Black Americans.

Finally, future research is needed that examines the relationships between structural racism and the self-management of other chronic conditions of which African Americans are faring poorly—e.g., hypertension, asthma, arthritis, obesity. These research efforts can help to narrow the widening gap between African Americans and non-Hispanic Whites in their morbidity and mortality rates in older age.

**Conclusion**

This grounded theory study was unique in its use of focus groups and individual interviews to identify the experiences and meanings that African American seniors
scribe to their early life experiences with structural racism, and additionally to explore their later life experiences with diabetes and diabetes self-management. By utilizing an insider’s perspective, and using participants’ voices to describe the experiences and events that have shaped their lives, as well as their approaches to diabetes, the findings derived from this study have expanded upon existing literature. Gains have been made regarding structural racism, the life course, and diabetes self-management among African American seniors. This study has deepened our understanding of the ways in which African Americans seniors identify threats, learn to navigate adversity, and take control of themselves despite living within a social environment that has structurally limited them. It has provided insight into their ways of dealing with a diabetes condition that constantly threatens to limit their lives.
### Appendix 1

#### Table of Literature Reviewed

<table>
<thead>
<tr>
<th>Authors</th>
<th>African American Sample</th>
<th>Cultural Context Described</th>
<th>Cultural Dimensions Addressed in the Culturally-Tailored Intervention</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agurs-Collins et al., 1997</td>
<td>N=64 African Americans Ages=55-79 years</td>
<td>Mass availability of high-fat and high-salt foods in African American communities</td>
<td>Deep structures</td>
<td>Results at three months indicated a significant net difference in mean HbA1c, weight, physical activity, and dietary intake of saturated fat and cholesterol between the experimental and control groups. Results for HbA1c and weight remained statistically significant at six months.</td>
</tr>
<tr>
<td>Anderson-Loftin et al., 2012</td>
<td>N=74 African Americans Mean Age=58.9 years (40-77 years)</td>
<td>Rural environment as a place that promotes obesity and makes weight loss difficult</td>
<td>Deep structures</td>
<td>Statistically significant reductions in BMI. At six months, weight decreased a mean of four pounds for experimental group, compared to an increase of four pounds for the control group. Experimental group lowered high-fat dietary behaviors. No significant differences in A1c between groups.</td>
</tr>
<tr>
<td>Authors</td>
<td>African American Sample</td>
<td>Cultural Context Described</td>
<td>Cultural Dimensions Addressed in the Culturally-Tailored Intervention</td>
<td>Results</td>
</tr>
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<tr>
<td>Collins-McNeil et al., 2012</td>
<td>N=12 African Americans</td>
<td>Church as a central institution in the African American community</td>
<td>Surface structures</td>
<td>Significant increases in self-reported medication adherence, healthy eating and foot care adherence. Increase in HbA1c from baseline to post-intervention. No significant differences in physical activity or blood glucose monitoring.</td>
</tr>
<tr>
<td>Cummings et al., 2013</td>
<td>N=200 African American women</td>
<td>Mistrust of health care providers</td>
<td>Deep structures</td>
<td>Hypothesized to demonstrate improvements in HbA1c, and psychosocial factors that will facilitate long-term DSM success.</td>
</tr>
<tr>
<td>Keyserling et al., 2000</td>
<td>N=200 African American women</td>
<td>Socio-cultural mismatch in available diabetes self-management programs</td>
<td>Surface structures</td>
<td>Participants found this intervention to be culturally relevant.</td>
</tr>
<tr>
<td>Authors</td>
<td>African American Sample</td>
<td>Cultural Context Described</td>
<td>Cultural Dimensions Addressed in the Culturally-Tailored Intervention</td>
<td>Results</td>
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<tr>
<td>Melkus et al., 2010</td>
<td>N=109 African American women</td>
<td></td>
<td>Surface structures</td>
<td>HbA1c improvement was seen in both the intervention and usual care groups from baseline to 3 months, but returned to near baseline values for the control group. The experimental maintained glycemic control at 24 months.</td>
</tr>
<tr>
<td></td>
<td>Ages=48 ± 10 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Samuel-Hodge et al., 2009</td>
<td>N=201 African Americans</td>
<td>African American church as an established institution that is suitable for health promotion</td>
<td>Surface structures</td>
<td>HbA1c significant at 8 months, but not significant at 12 months. No difference between groups in with dietary, except in percentage of calories from trans fats. At 12 months, little change in light and moderate physical activity. Significant differences in diabetes knowledge.</td>
</tr>
<tr>
<td></td>
<td>Mean Age=59 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Authors</td>
<td>African American Sample</td>
<td>Cultural Context Described</td>
<td>Cultural Dimensions Addressed in the Culturally-Tailored Intervention</td>
<td>Results</td>
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</tr>
<tr>
<td>Tang et al., 2005</td>
<td>N=56 African Americans Mean Age=64.5 years (36-82 years)</td>
<td>Lower rates of routine A1c, lipid testing and retinopathy screening compared to Caucasians</td>
<td>Surface structures</td>
<td>Significant improvements for following a healthy diet, carb spacing, using insulin as recommended, and achieving diabetes-specific quality of life. At 1-year follow-up, additional improvements were found in glycemic control, serum cholesterol, and LDL cholesterol levels.</td>
</tr>
<tr>
<td>Two Feathers et al., 2005</td>
<td>N=71 African Americans Mean Age=60.9 years (±13.9 years)</td>
<td>Disinvestment and outmigration in Detroit, leading to physical activity and healthy eating barriers</td>
<td>Deep structures</td>
<td>Statistically significant improvements were found in dietary knowledge and behaviors, physical activity knowledge, and HbA1c levels. No changes were found in physical activity levels or diabetes-specific quality of life.</td>
</tr>
</tbody>
</table>
Appendix 2

Eligibility Determination Form

By completing this form, you agree to be screened for possible inclusion in this research study. Please answer the following questions to the best of your ability:

<table>
<thead>
<tr>
<th>Race/Ethnicity:</th>
<th>Age:</th>
</tr>
</thead>
<tbody>
<tr>
<td>How long have you had diabetes?</td>
<td>Who told you that you had diabetes?</td>
</tr>
<tr>
<td>Other than type 2 diabetes, what illnesses do you have? (For example: high blood pressure, arthritis, cancer, etc.)</td>
<td></td>
</tr>
<tr>
<td>What medical treatments are you currently receiving? (For example: dialysis, chemotherapy etc.)</td>
<td></td>
</tr>
</tbody>
</table>

Please select YES or NO if you are able to do the following:

<table>
<thead>
<tr>
<th>Prepare your own meals</th>
<th>□ YES □ NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prepare your own medications</td>
<td>□ YES □ NO</td>
</tr>
<tr>
<td>Be physically active (For example: walk, exercise, work in your garden, etc.)</td>
<td>□ YES □ NO</td>
</tr>
<tr>
<td>Check your own blood sugars at home (Regardless if you have the equipment at home right now, we would like to know if you are able to prick your own finger and use a glucometer.)</td>
<td>□ YES □ NO</td>
</tr>
</tbody>
</table>

FOR RESEARCH USE ONLY:
- □ Understands study
- □ HbA1c _________ %
- □ Enrolled □ Not Enrolled
African American Older Adults
with Type 2 Diabetes:

Structural Racism and
Diabetes Self-Management Study

REQUEST TO PARTICIPATE IN RESEARCH STUDY

If you are:
☑️ an African American man or woman
☑️ age 55 years or older
☑️ and you have type 2 diabetes...

You may be eligible to participate in a RESEARCH STUDY that seeks to understand your experiences with structural racism, and your experiences with having and managing diabetes. Structural racism is related to laws and systems that determine the ways people of color receive goods and services. Examples are Jim Crow, segregation and integration, and the Civil Rights Movement.

Participation consists of attending an information meeting, focus group and an individual interview. Participation is on a voluntary and confidential basis. Your participation in this study will have no effect on your relationship with [redacted] Senior Center or any of the services that you receive at the center.

THE NEXT INFORMATION SESSION WILL BE HELD ON:

If you are eligible and participate in the study, you will receive a gift bag of diabetes-related items and product samples.

The research is being conducted by a doctoral nursing student in the UCLA School of Nursing.

For more information about this research study, please contact:
Kia Skrine Jeffers, PhD(c), MSN, RN

UNIVERSITY OF CALIFORNIA, LOS ANGELES
SCREENING CONSENT SCRIPT

Structural Racism and Diabetes Study

Thank you for your interest in this research study. I am Kia Skrine Jeffers, a student from the UCLA School of Nursing. Before I begin the screening I would like to tell you a little bit about the research. This research is looking at your experiences with racism growing up, and your experiences with diabetes as an older adult. If you qualify for the study, we will ask you to attend a focus group within the next week, and a one-on-one interview within one to two weeks after the focus group. The focus group will take place in a group setting with you and two to four other seniors, and will last about an hour. The interview will take place with you and the researcher in a private room, and will also last about an hour. Questions in the focus group will be about things that happened in the communities where you lived. Questions in the interview will dig deeper into those things.

If you would like to be screened for this study, please stay in this room and we will continue with the screening process. If you are not interested in being screened, or would like to have some time to think about it, you are welcome to take a flyer with you. My phone number and email address are on the flyer, and you are welcome to contact me at a later time. It is up to you to decide if you would like to be screened for this study.

[Distribute the recruitment flyer to anyone who is leaving.]

Today’s screening will take about 20 minutes. Your answers to the screening questions will be confidential. No one will know your answers except for the research team. First, you will fill out a form that asks about your race, age, diabetes and other medical conditions, and your ability to take care of your diabetes on your own. You do not have to answer any questions you do not want to answer or are uncomfortable with answering, and you may stop at any time. When the form is complete, I will meet with each of you one-by-one to go over the form and to ask, “What do you understand about this study?” Finally, if you meet the criteria up to that point, I will check your blood sugar. The blood sugar test will take 5 minutes, and your blood sample will be destroyed when the test is done. If you are eligible and decide to join the study, you will be given a consent form to sign, a form that asks questions about you—such as places where you have lived, your marital status, educational level, etc. I will also collect your contact information. If you do not enroll in the study for any reason, all of the forms that you completed today will be destroyed.

[If the potential participant does not meet the criteria at any point throughout the screening process, I will thank them for their interest, and explain why they are ineligible for this study.]

Do you have any questions about the screening or research? If you think of any questions later, I will give you a flyer that has my contact information on it. If you complete the consent form, you will receive a copy, and my contact information is on that as well. There is also a number for the Office of the Human Research Protection Program at UCLA listed if you need it.

Thank you again for your willingness to be screened for this study.
## Demographic Data Form

**Year of Birth:** 
**Location of Birth (City, State):**

Please list other cities and states where you have lived AND the approximate years (or ages) that you lived there (For example: Chicago, IL 1950-1960, or Chicago, IL ages 6-16 years old).

**Gender:**  
- □ MALE  
- □ FEMALE

**Have you ever served in the U.S. military?**  
- □ YES  
- □ NO

**Marital Status:** (Please check only one.)  
- □ Never married  
- □ Married  
- □ Separated/Divorced  
- □ Widowed

**Highest Level of Education Completed:**  
- □ No schooling completes  
- □ 8th grade or less  
- □ Some High School  
- □ High School graduate/GED  
- □ Technical/Trade School  
- □ Some college credit, did not graduate  
- □ Associate’s degree  
- □ Bachelor’s degree  
- □ Graduate level degree (Master’s, PhD, etc.)

**Annual Income:**  
- □ Less than $5000  
- □ $5000 to under $7,500  
- □ $7,500 to under $10,000  
- □ $10,000 to under $12,500  
- □ $12,500 to under $15,000  
- □ $15,000 to under $20,000  
- □ $20,000 to under $25,000  
- □ $25,000 to under $30,000  
- □ $30,000 to under $35,000  
- □ $35,000 to under $40,000  
- □ $40,000 to under $50,000  
- □ $50,000 to under $60,000  
- □ $60,000 to under $75,000  
- □ $75,000 to under $100,000  
- □ $100,000 or more
Appendix 6

Sample of Semi-structured Focus Group Questions:

- Please describe what life was like for you as a child.
  - What types of things were in your community?
  - What types of activities did you do?
  - Please tell me about your experiences in school.
- Please describe your experiences with others in your community.
  - …with your friends
  - …with your neighbors
  - …with businesses such as stores and banks
  - …with places where you worked
  - …with social service people such as police and public works
- Please tell me your thoughts about the recent killings of young, Black males like Trayvon Martin.

Sample Semi-structured Individual Interview Questions:

- Please tell me what your experiences were with diabetes before you were diagnosed.
  - What did you know about diabetes?
  - Who did you know with the condition?
  - What do you remember about their experiences with diabetes?
- Please describe what happened when your doctor told you that you had diabetes.
  - What did the doctor say?
  - What do you remember thinking?
  - What do you remember feeling?
- What has your personal experience been with diabetes?
### Appendix 7

**APPROVAL NOTICE**  
**New Study**

<table>
<thead>
<tr>
<th>DATE:</th>
<th>9/23/2014</th>
</tr>
</thead>
</table>
| TO:   | KIA SKRINE JEFFERS  
SCHOOL OF NURSING |
| FROM: | ALISON MOORE, MPH, MD  
Chair, SGIRB |
| RE:   | IRB#14-000882  
The Impact of Structural Racism Experienced in Early Life on the Diabetes Self-Management Behaviors of African Americans in Their Later Years: A Grounded Theory Study |

The UCLA Institutional Review Board (UCLA IRB) has approved the above-referenced study. UCLA's Federawide Assurance (FWA) with Department of Health and Human Services is FWA00004642.

**Submission and Review Information**

<table>
<thead>
<tr>
<th>Type of Review</th>
<th>Full Board Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approval Date</td>
<td>8/22/2014</td>
</tr>
<tr>
<td>Expiration Date of the Study</td>
<td>8/25/2015</td>
</tr>
</tbody>
</table>

**Regulatory Determinations**

- Waiver of Signed Informed Consent - The UCLA IRB waived the requirement for signed informed consent for screening under 45 CFR 46.117(c)(2).

Documents Reviewed Included, but were not limited to:
Important Note: Approval by the Institutional Review Board does not, in and of itself, constitute approval for the implementation of this research. Other UCLA clearances and approvals or other external agency or collaborating institutional approvals may be required before study activities are initiated. Research undertaken in conjunction with outside entities, such as drug or device companies, are typically contractual in nature and require an agreement between the University and the entity.

General Conditions of Approval
As indicated in the PI Assurance as part of the IRB requirements for approval, the PI has ultimate responsibility for the conduct of the study, the ethical performance of the project, the protection of the rights and welfare of human subjects, and strict adherence to any stipulations imposed by the IRB.

The PI and study team will comply with all UCLA policies and procedures, as well as with all applicable Federal, state, and local laws regarding the protection of human subjects in research, including, but not limited to, the following:

- Ensuring that the personnel performing the project are qualified, appropriately trained, and will adhere to the provisions of the approved protocol;
- Implementing no changes in the approved protocol or consent process or documents without prior IRB approval (except in an emergency, if necessary to safeguard the well-being of human subjects and then notifying the IRB as soon as possible afterwards);
- Obtaining the legally effective informed consent from human subjects of their legally responsible representative, and using only the currently approved consent process and stamped consent documents, as appropriate, with human subjects;
- Reporting serious or unexpected adverse events as well as protocol violations or other incidents related to the protocol to the IRB according to the OHRPP reporting requirements;
- Assuring that adequate resources to protect research participants (i.e., personnel, funding, time, equipment and space) are in place before implementing the research project, and that the research will stop if adequate resources become unavailable;
- Arranging for a co-investigator to assume direct responsibility of the study if the PI will be unavailable to direct this research personally, for example, when on sabbatical leave or vacation or other absences. Either this person is named as co-investigator in this application, or advising IRB via webIRB in advance of such arrangements.
References


http://www.yale.edu/ynhti/curriculum/units/1979/2/79.02.04.x.html


Williams, D. & Leavell, J. (2012). The social context of cardiovascular disease: Challenges and opportunities for the Jackson Heart Study. *Ethnicity & Disease, 22*(Suppl. 1), S1-5-S1-21.


