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African American End-Stage Renal Disease And Medication Adherence: What Are The Effects Of Everyday Racism?

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AFRICAN AMERICAN END-STAGE RENAL DISEASE AND MEDICATION
ADHERENCE: WHAT ARE THE EFFECTS OF EVERYDAY RACISM?

by

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DEDICATION

I dedicate this to my husband, Jeffrey. He has stuck by me for 26 years and encouraged me throughout the doctoral process. He has been unwavering in his support. As W.H. Auden's poem states, "He is my North, my South, my East and West, My working week and my Sunday rest, My noon, my midnight, my talk, my song." Somehow a witty guy met a sarcastic woman and the rest is history.

I also dedicate this to my sweet Seth and Elise. They have understood when I missed first days of school, school performances, and slept in late on countless Saturdays. When I cried because it was all too much, they brought me food and cuddled with me in bed. Many times I have left the house in a rush and they have called after me telling me that I am amazing. They often tell me I am the BEST and promise to call me Dr. Mommy on occasion.

I also dedicate this to my mother and father in-law, Mary Carolyn and Billy Savage. Without their help taking care of Seth and Elise, I could not have left every week for South Carolina for four years. I knew when I could not be home that my children were always nurtured, loved, and safe. When I spent many a night in South Carolina, they tucked them in bed at our home, fed them breakfast, and sent them off to school. I am eternally grateful that my children have such amazing grandparents.

So it is with this cadre of wonderful people, my family, that I embrace this honor. A poor Southern girl who spent much of her childhood in poverty has now reached her highest professional aspirations. I am so lucky to have a family who believes in me and is so kind and supportive. Thank you!

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I want to acknowledge my two mentors in this journey. First, Dr. Robert Blundo is the reason that I decided to pursue my doctorate. When I was an undergraduate social work student, he pulled me aside after class one day and told me that I should get my PhD. As a poor kid from Georgia, I did not believe him. However, he believed in me and generated opportunities for me to succeed in research and conference presentations. I am forever grateful. Second, Dr. Teri Browne mentored me throughout my doctoral studies. From the first day of class she has been a constant source of support, encouragement, and tutelage. She helped me craft my first publication during my first year in the program, taught me to write concisely, created opportunities for me to grow and excel as an academician, and has **always** been on my side. She believed in me when it was really difficult for me to believe in myself. Without the two of you, I would not be here!

I also want to acknowledge Dr. Ronald Pitner and Dr. Dana DeHart. Dr. Pitner has provided guidance and insight both in the classroom and throughout the dissertation process. He has reminded me to temper my language and be clear about my ideas conceptually. Most of all he has supported my intellectual endeavors. Dr. DeHart agreed to help me through the dissertation process when I needed an advocate the most. Her belief in me and wise counsel during my dissertation are irreplaceable. She taught me that less is more and her instinct for clarity has made me a better writer.

ABSTRACT

This dissertation explored the racial medication adherence disparity in end-stage renal disease (ESRD) patients. Prior research suggests that there are poor rates of medication adherence in the African American ESRD population. However, the reasons for this racial inequity are not understood. This dissertation explored the impact of everyday racism in the healthcare system in general and dialysis centers in particular on medication adherence. To gain an understanding of the possible contribution of everyday racism to medication nonadherence, Critical Race Theory (CRT) was used as the theoretical foundation of the study.

A total of 46 African American ESRD patients participated in the study. Twenty seven patients participated in semi-structured, in-depth interviews. Some participants did explicate that they experienced everyday racism in the healthcare system and such experiences impacted their medication adherence. Additionally, all 46 participants completed a survey regarding self-reported medication adherence and everyday racism in the healthcare setting. There was a statistically significant negative relationship between the two constructs. The results of the Pearson's correlation showed a significant negative relationship ($r = -.477, p < .01$) between medication adherence and everyday racism in the healthcare system.

This study has several limitations. A convenience sample was used for both the qualitative and quantitative portions. Additionally, the quantitative study used a nonexperimental cross-sectional design with a small sample. However, this is the first

study to ever examine the impact of everyday racism on medication adherence within the African American ESRD population. Furthermore, these results both qualitatively and quantitatively suggest that everyday racism did impact the medication adherence of the participants. Thus further study is needed to explore this phenomenon since medication nonadherence in the ESRD population results in increased hospitalizations, morbidity, and mortality.

Further study could result in new information that could be used to generate novel interventions to address everyday racism in the healthcare system. Social workers are uniquely qualified given their educational training which focuses on cultural competency and their ethical obligation to address social injustice. Additionally, every dialysis patient has a social worker to help them achieve positive health outcomes. Thus, social workers are equipped to work with African American ESRD patients, healthcare providers, and dialysis clinicians to design and implement possible future interventions to achieve medication adherence racial parity within the ESRD population.

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LIST OF ABBREVIATIONS

CGT.....	Constructivist Grounded Theory
CLS	Critical Legal Studies
CRT.....	Critical Race Theory
ESRD	End-Stage Renal Disease
LIS.....	Low Income Subsidy
NASW.....	National Association of Social Workers
NKF.....	National Kidney Foundation
PEM	Patient Empowerment Meeting
SAKC.....	Seattle Artificial Kidney Center
USPHS	United States Public Health System
USRDS.....	United States Renal Data System

CHAPTER 1

INTRODUCTION

This dissertation study examined the possible role of everyday racism on the medication adherence of African American ESRD patients. This chapter begins with a discussion of the disease process of kidney disease and current treatment modalities. Next, the problem statement, purpose of research, proposed conceptual model, and research questions are articulated. The chapter ends with an explication of the proposed theoretical foundation of the study, the relevance of the study to social work, and the significance of the proposed study to the larger body of scholarly literature.

Background

Chronic kidney disease is the ninth leading cause of death in the US (Centers for Disease Control, 2016). Chronic kidney disease is diagnostically measured in five stages with each increasing stage representing a reduction in kidney function (Coresh & Eustace, 2008; National Kidney Foundation, 2016). ESRD is defined as the permanent failure of the kidneys and is the fifth and final stage of chronic kidney disease (Coresh & Eustace, 2008; Himmelfarb, Chuang, & Schulman, 2008; National Kidney Foundation, 2016). The current medical treatment for ESRD is dialysis or kidney transplantation (USRDS, 2015). The majority of African American ESRD patients are on hemodialysis. Hemodialysis filters patients' blood through a dialysis machine (Mayo Clinic Staff, 2010). Excess fluids and waste products are collected in the machine. ESRD patients get

dialysis at least three times a week for four to six hours (Browne, 2012). Hemodialysis requires a complex medication regimen and a very restrictive diet.

According to the United States Renal Data System (USRDS) (2015), there are 661,648 prevalent cases of ESRD in the US. This is a 3.5% increase from 2012 and a 68% increase from 2000 (USRDS, 2015). ESRD cases have continued to increase by 21,000 people every year since 2010 (USRDS, 2015). Of these prevalent cases, African Americans are disproportionately represented. The prevalence of ESRD per million of African Americans in the US is 5,584 (USRDS, 2015). Comparatively, the prevalence of ESRD per million of Whites in the US is 1,499 (USRDS, 2015). Thus, ESRD is nearly four times more prevalent among African Americans.

There is also marked regional clustering of African American ESRD. For example, in the Southern US, African Americans comprise 50% of the ESRD population (USRDS, 2015). This is significant because African Americans represent only 20% of the total population in the South (United States Census Bureau, 2011). Furthermore, African American ESRD patients are also less likely to successfully manage their medications compared to White ESRD patients (Browne & Merighi, 2010; Curtin, Svarstad, & Keller, 1999; Saran et al., 2003). However, the reasons for this racial inequity are not understood beyond proximal risk factors that include sociodemographic factors (age, gender, education, insurance, and income) and other risk factors (pill burden, depression, health literacy, patient satisfaction, and health beliefs).

Problem Statement

Medication adherence is defined as “the extent to which patients take medications as prescribed by their health care providers” (Osterberg & Blaschke, 2005). ESRD patients

who do not adhere to their medication regimen as prescribed suffer increased hospitalizations (Saran et al., 2003; USRDS, 2015), decreased quality of life (USRDS, 2015), and death (Browne, 2012; Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte, & De Geest, 2007). African American ESRD patients are less likely to successfully manage their medications compared to White ESRD patients (Browne & Merighi, 2010; Curtin, Svarstad, & Keller, 1999; Saran et al., 2003). ESRD patient medication adherence disparities are a significant public health problem.

Racial disparities in the quality of healthcare African Americans receive are well documented. Compared to Whites, studies have found that African Americans receive fewer cardiovascular procedures (Bell & Hudson, 2001; Canto et al, 2000; LaVeist, Morgan, Arthur, Plantholt & Rubinstein, 2002; Okelo et al., 2001; Petersen, Wright, Peterson, & Daley, 2002; Watson et al., 2001), fewer cerebrovascular tests and anticoagulant therapy (Mitchell, Ballard, Matchar, Whisnant & Samsa, 2000; Oddone et al., 1999), less comprehensive diabetes care (Baicker, Skinner & Chandra, 2005; Chin, Zhang & Merrell, 1998; Heisler, Smith, Hayward, Krein, & Kerr, 2003; Trivedi, Zaslavsky, Schneider, & Ayanian, 2005) fewer kidney transplants (Ayanian, Cleary, Weissman & Epstein, 1999; Kasiske, London & Ellison, 1998), lower quality hospital care (Fiscella & Saunders, 2015; Hasnain-Wynia et al., 2007), and are prescribed less pain medication (Heins, Heins, Grammas, Costello, Huang, & Mishra, 2006; Pletcher, Kertesz, Kohn, & Gonzales, 2008; Tod, Eaton, D'Adamo & Goe, 2000; Bernabei et al., 1998).

Additionally, some studies have found that African Americans perceive the healthcare system as racist, discriminatory, and unjust (Bhattacharya, 2012; Bird, & Bogart, 2001;

Hausmann, Jeong, Bost, & Ibrahim, 2008; LaVeist, Nickerson, & Bowie, 2000; Pathman, Fowler-Brown, Thaker, Ashkin, Corbie-Smith, 2006; Schlomann & Schmitke, 2007). Furthermore, studies have documented that African Americans are suspicious of the efficacy of prescribed medications (Lukoschek, 2003; Schrimshaw, Siegel, & Lekas, 2005; Siegel, Karus, & Schrimshaw, 2000).

There is also some evidence in the literature that an association between perceived racism/discrimination and medication nonadherence exists within the chronic disease context. Several studies indicate that perceived discrimination is a contributing factor to medication nonadherence in African American patients with chronic diseases such as type 2 diabetes (Bhattacharya, 2012; Dawson, Walker, Campbell & Egede, 2015), hypertension (Forsyth, Schoenthaler, Chaplin, Ogedegbe & Ravenell, 2014; Lewis, Askie, Randleman & Shelton-Dunston, 2010; Lukoschek, 2003), and HIV (Bogart, Wagner, Galvan, & Banks, 2010; Thrasher, Earp, Golin, & Zimmer, 2008). However, there are no studies that examine how perceived racism/racial discrimination relates to medication nonadherence for African American ESRD patients. Given the racial disparity in medication adherence in the ESRD population, the dire physical consequences of medication nonadherence, and the existence of racial discrimination in the healthcare system, it is important to inquire about the possible role of racial discrimination.

Purpose of Research & Methodology

The purpose of this mixed methods dissertation study was two-fold. The first was to conduct a qualitative study comprised of semi-structured in-depth interviews with African American ESRD patients regarding possible experience of everyday racism in

the healthcare system. The second was to conduct a correlational quantitative study to ascertain if there was a statistical relationship between participants' medication adherence and everyday racism in the healthcare system.

A mixed methods approach was chosen for three reasons. First, in-depth interviews allow for the elucidation of nuanced issues that might link racism to medication adherence (Creswell & Clark, 2011). Second, in-depth interviews give participants the opportunity to include their voices in the research process. Third, a quantitative component provides a more comprehensive account of the studied phenomenon and allows the researcher to build on the information gleaned from the qualitative component, thus increasing the credibility of the findings (Creswell & Clark, 2011).

Qualitative Methods

A constructivist grounded theory (CGT) approach guided the interview process and data analysis. CGT was chosen as the methodology because it provides a systematic approach to delve into the experiences of everyday life of participants. CGT also acknowledges the impact of the researcher on the research process (Charmaz, 2000, 2006, 2011). Therefore, both data collection and analysis are the result of the shared experiences and relationships among participants and researcher (Charmaz, 2000, 2001, 2006, 2011; Charmaz & Mitchell, 1996). Theoretical understanding occurs when researchers ponder, ask old questions, generate new questions, return to the field to gain clarification, and make comparisons within the data. Charmaz (2011) states, "When you theorize, you reach down to fundamentals, up to abstractions, and probe into experience. The content of theorizing cuts to the core of studied life and poses new questions about it" (p.135). Since the possible role of everyday racism on medication adherence within

the African American ESRD population is a phenomenon we know very little about, a CGT approach allowed for an in-depth understanding (Charmaz, 2006, 2011).

Quantitative Methods

Data for the quantitative portion of the study was obtained using the two scales: Medication Adherence Reporting Scale MARS-5 (see Appendix A) and Discrimination in Medical Settings Scale DMS (see Appendix B). Both scales were administered to each participant after the in-depth interview. It was hypothesized that African American ESRD patients who reported high incidences of everyday racial discrimination in the healthcare system would report lower adherence to their medication regimen. The statistical test, Pearson's correlation coefficient, was conducted to statistically test the hypothesis. The Pearson's correlation coefficient is a measure of the strength of association between two variables and is denoted by r . All statistical tests were conducted using the statistical data analysis package SPSS version 24.

Conceptual Model

The conceptual model for this dissertation is presented in Figure 1.1. Since critical race theory (CRT) articulates that racism is ordinary and pervasive throughout society, the model begins with racism which is positioned at the top of the model. Next, everyday racism in the healthcare system flows from racism. This is supported by (Essed's 1991) explication that everyday racism is the everyday manifestation of racism. Everyday racism in the healthcare system is defined as those chronic mistreatments, daily hassles, and slights based on membership in a race or ethnic group which African Americans experience within the healthcare system (Essed, 1991; Williams & Mohammed, 2010). Examples of everyday racism in the healthcare system include being treated with less

respect, treated as less intelligent, and not listened to by healthcare providers based on your race. Next, it is posited that everyday racism in the healthcare system leads to distrust of the quality and efficacy of prescribed medication. As mentioned above, distrust of the quality and efficacy of prescribed medication has been explicated in the literature on chronic diseases other than ESRD (Lukoschek, 2003; Schrimshaw, Siegel, & Lekas, 2005; Siegel, Karus, & Schrimshaw, 2000). Furthermore, it is postulated that distrust in medication quality and efficacy work in concert with the identified risk factors in the literature to decrease medication adherence. The variables that are typically cited

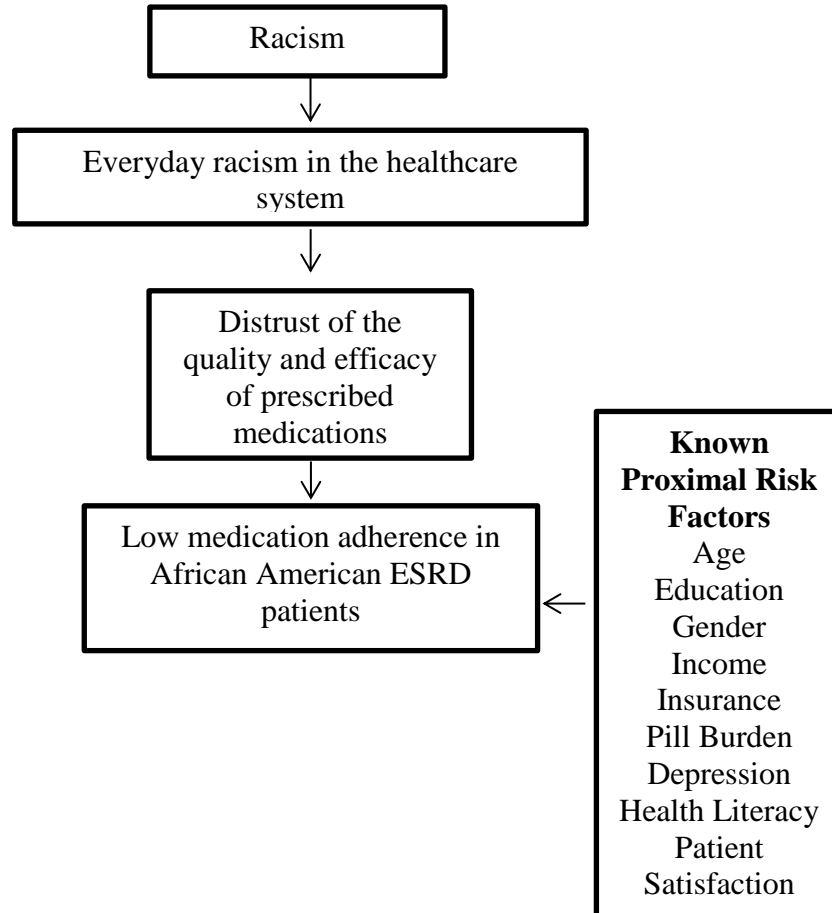


Figure 1: Conceptual Model: Role of Everyday Racism in the Medication Adherence of African American ESRD Patients

as risk factors include: age, education level, gender, income, insurance, pill burden, depression, health literacy, patient satisfaction, and health beliefs (Bame, Petersen, & Wray, 1993; Browne, 2012; Curtin, Svarstad, & Keller, 1999; Kalichman, Ramachandran, & Catz, 1999; Schmid, Hartmann & Schiffel, 2009).

Research Questions & Hypothesis

Research Questions for Qualitative Portion. The following research questions were addressed:

- 1) Do African American ESRD patients experience everyday racism in the healthcare setting?
- 2) If so, does everyday racism influence their medication adherence?
- 3) In what way does everyday racism influence their medication adherence?
- 4) If everyday racism does not influence their medication adherence, what does?

Hypothesis for Quantitative Portion. It was hypothesized that African American ESRD patients who reported high incidences of everyday racial discrimination in the healthcare system would report lower adherence to their medication regimen.

Definition of Terms

ESRD is defined as kidney failure that necessitates dialysis for survival (Hallan & Vikse, 2008). Hemodialysis is the process where a patient's blood is filtered through the dialysis machine to remove excess fluids and waste products (Mayo Clinic Staff, 2010). Medication adherence is defined as "the extent to which patients take medications as prescribed by their health care providers" (Osterberg & Blaschke, 2005). Medication adherence will be assessed using the Medication Adherence Report Scale (MARS) (see Appendix A).

The healthcare system is defined as the particular organizations and staff from which the dialysis patients receive care such as the pharmacy and dialysis center. Staff generally includes the following: social worker, dietitian, nurse, nephrologist, pharmacist, pharmacy technician, and dialysis technician. A dialysis clinic is defined as the medical setting that hemodialysis patients must attend to receive dialysis on average three times a week for three to four hours each day for the rest of their lives.

Everyday racism is defined as systematic, recurrent, routine, and normalized mistreatment based on a person's racial group membership (Essed, 1991). Everyday racism can include both mundane annoyances that may be quickly forgotten or severe incidences that are never forgotten (Essed, 1991; Feagin & Sikes, 1994; Swim et al., 1998). Everyday racism in the healthcare system is defined as those chronic mistreatments, daily hassles, and slights based on membership in a race or ethnic group which African Americans experience within the healthcare system (Essed, 1991; Williams & Mohammed, 2010). Everyday racism in the healthcare system will be assessed using the Discrimination in Medical Settings (DMS) Scale (see Appendix B).

Theoretical Foundation

The theory that informed the approach to understand the possible influence of everyday racism on medication adherence is critical race theory (CRT). The genesis of CRT occurred in the 1970's following the political and legal achievements of the Civil Rights Movement. Two legal scholars, Derrick Bell and Alan Freeman, began to question the paucity of economic and societal gains experienced by African Americans (Delgado & Stefancic, 2012; Kolivoski, Weaver & Constance-Huggins, 2014). During

this time, many legal scholars, who had been active in the Civil Rights Movement, began to critically analyze the US legal system (Constance-Huggins, 2014; Unger, 1983).

These “radical” legal scholars coined this analysis Critical Legal Studies (CLS) (Delgado & Stefancic, 2012; Unger, 1983).

CLS scholars asserted that the legal system was neither objective nor just (Hutchinson, 1989; Unger, 1983). Instead, they argued that legal ideology, doctrines, and practice perpetuated societal inequality through maintaining the status quo which privileged the politically and economically powerful (Crenshaw, 1988; Hutchinson, 1989; Unger, 1983). Bell and Freeman agreed that political and economic power were important factors in maintaining societal inequality. However, they noted that racism was egregiously absent from CLS scholars’ critiques of the legal system (Delgado & Stefancic, 2012).

Bell and Freeman argued that racism is entrenched and ubiquitous in historical and contemporary US society. Thus, racism is also pervasive in the legal system, which necessitates its inclusion in the critique of the legal system. To do otherwise, they contended, perpetuated racial inequality. Bell (1976, 1979) and Freeman (1977) began exploring the relationship among race, racism, and power and publishing their thoughts in law journals. They wrote that the ideas of objectivity and fairness attributed to and espoused by the legal system were apocryphal and served to mask the invisible privileges afforded Whites at the expense of people of color. They explained that race was not a natural category. Instead it is a social construction used as a tool to establish and continue White supremacy in the US. The resulting racial hierarchy influences legal doctrines and practice. Bell (1976, 1979) and Freeman (1977) asserted that this influence

extends to every level of the legal system from local law enforcement to the US Supreme Court and the US Constitution. They postulated that until racism is “unveiled” (Dubois, 2003), acknowledged, and actively eradicated, it will persist.

Soon, like-minded law professors, lawyers, and students engaged in critical discourse with Bell and Freeman. In 1989, the first critical race theory workshop was held in Madison, Wisconsin (Delgado & Stefancic, 2012). Since then critical race scholars have urged scholars in disciplines other than law to examine the influence of racism in their area of study. The rationale is that since racism is endemic to society in the US then it affects every aspect of society. Thus, it must impact the educational system, public health system, and political system. As a result of this call to investigate, many other disciplines such as education, women’s studies, sociology, political science, and social work have become involved in the CRT movement (Delgado & Stefancic, 2012).

Relevance of CRT to Proposed Research

There are several assumptions of CRT that informed this research. First, CRT postulates that racism is an integral part of the social fabric of the United States. Thus, it is conceivable that the African American ESRD patients experience racism in the healthcare system. Second, CRT assumes that racism is an everyday and ordinary life occurrence for people of color and determines social outcomes. CRT scholars refer to this ordinariness of racism as the “normal science” of living in US society (Delgado & Stefancic, 2012). This assumption relates to the conceptualization in this study that racism influences medication adherence because if racism is an everyday life occurrence for African Americans, it is plausible that racism may play a role in their medication adherence. Third, CRT posits that racism is not acknowledged as a problem by the

dominant White group. Since racism is not acknowledged, it is difficult to eradicate. This assumption relates to the conceptualization of the racial disparity in medication adherence because racism, a distal, societal risk factor, is rarely studied in the field of medication adherence. Instead, the focus is generally on proximal sociodemographic factors and behavioral factors. Sociodemographic factors are generally unchangeable or difficult to change such as age, gender, education, and income. However behavioral factors such as depression, pill burden, lack of health literacy, lack of patient satisfaction, health beliefs, and social support are often the site for interventions (Browne & Merighi, 2010; Hu, Juarez, Yeboah & Castillo, 2014; Matteson & Russell, 2010; Simmons-Morton, McLeroy & Wendel, 2012). These interventions often put the responsibility on the individual African American ESRD patient for the disparity. The study's conceptualization puts the responsibility on the unacknowledged racism. The fourth concept that was salient to this research is structural determinism. Structural determinism refers to the CRT idea that the racist structure of the US determines, in great part, the outcomes of individuals. This concept relates to the conceptualization of the problem because it gives credence to the idea that health outcomes such as medication adherence may be influenced by racism in society.

There are also three main mandates of CRT that are integral to and guided this research. First, CRT requires that research “centers the margins” (Delgado & Stefancic, 2012, p.10; Ford & Airhihenbuwa, 2010). This means that the main focus of research using CRT should be the perspectives of people of color; those who have been marginalized (Ford & Airhihenbuwa, 2010). This achieved this mandate through eliciting the perspectives of people of color through in-depth interviews. It was an

opportunity for the participants to relate and reflect upon the details of their experiences in a respectful context.

The second mandate is that it must be understood that people of color have a unique voice, a vastly different perspective than White people. The unique voice of color refers to the CRT belief that people of color experienced a different history and currently experience a different reality than White people. Hence, research should not only bring the perspectives of people of color to the fore but must acknowledge that their perspectives are quite different. This mandate relates to the conceptualization of the problem because to understand the mechanisms of the medication adherence disparity, researchers must engage African Americans in how their reality regarding racism, which is informed by a history of oppression, impacts their daily lives including their health outcomes.

The third mandate is that CRT requires social action to challenge racial injustice. Bell and Freeman define social action broadly and include academic publication as a form of acknowledging and examining racism. Although CRT has long been adopted as a theoretical and practical stance for education, women's studies, and political science, CRT is a nascent to the field of social work and public health (Ford & Airhihenbuwa, 2010). This is the first time to the researcher's knowledge that CRT has been used to examine everyday racism within the African American ESRD population. Bringing a critical analysis to this topic is the beginning of social action as defined by CRT.

Relevance of Research to Social Work

This study is relevant to social work for several reasons. Fundamentally, nephrology

social work with dialysis populations is a critical practice area for the profession, as the only Medicare mandate for a Master's level social worker on treatment teams is found in dialysis and kidney transplant centers (Browne, 2012). Every single dialysis patient has a social worker to help them ameliorate the psychosocial barriers to treatment outcomes, including medication nonadherence. The results of this study can help inform nephrology social work practice and help dialysis social workers help their patients take their medications as prescribed.

There is a gap in the social work literature base concerning the possible role of everyday racism in the medication taking of African American ESRD patients. As social workers, we are ethically bound to conduct research to elucidate knowledge gaps pertaining to issues that affect our clients (NASW, 2008). Additionally, a foundational, core value of the social work profession is social justice. According to the National Association of Social Workers (NASW, 2008), social justice entails “access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people” (p. 3). Furthermore, social workers are ethically bound to challenge social injustice in any form including racial oppression (NASW, 2008). Gaining knowledge about a social injustice is the beginning step for social change. Once an injustice is acknowledged, efforts can be made to confront and eradicate the injustice. This study provided the first exploration of racism within the healthcare system experienced by African American ESRD.

Significance of Study

Studying medication adherence in the ESRD population is important because the disease presents several unique burdens not experienced by patients of other common

chronic diseases such as hypertension, diabetes, and HIV. ESRD patients have the highest pill burden (Chiu et al., 2009; Neri et al., 2011; Schmid, Hartmann, & Schiff, 2009) and a multitude of body systems are impacted (Brenner, 2008). Furthermore, patients spend much time in the dialysis clinic. Unlike other mentioned chronic diseases, patients with ESRD **must** dialyze an average of three days per week for three to four hours each day and take their medications so they can undergo dialysis without medical complications (USRDS, 2015). If they do not, death is certain. Thus, ESRD patients literally depend on dialysis and their medication regimens for survival.

Studying medication adherence in the African American ESRD population is important for three reasons. First, there is a racial disparity in medication adherence in the ESRD population. African Americans adhere less to their medication regimens. Second, low medication adherence results in increased mortality, increased hospitalizations, and decreased quality of life. Third, in addition to the burden nonadherence creates for the individual ESRD patient, it can be costly. Almost all ESRD patients are enrolled in Medicare when they are diagnosed. Therefore, taxpayers pay for the majority of the care ESRD patients receive in the form of dialysis, hospitalizations, and some prescriptions. If patients do not follow their medication regimens, myriad medical complications can occur resulting in expensive medical intervention such as hospitalization (Center for Medicare and Medicaid Services, 2014; USRDS, 2015).

Fourth, as Bell (1976, 1979) and Freeman (1977) have articulated, African Americans have experienced a different history than Whites, a history of subjugation and oppression. In addition, the continued presence of racism means that African Americans also experience a different reality than Whites. A reality suffused with racism. Thus, a

critical analysis of medication adherence through the lens of racism is warranted to ascertain its possible influence on the medication adherence disparity in the African American ESRD population. Such critical analysis does not currently exist in the literature.

The following is a review of the extant literature. The literature review includes a brief summary of historical racism and discrimination that has occurred in the US in the healthcare system in general and towards ESRD patients in particular. Much historical racism and discrimination occurred in the Southern US. The South was the location of the slave economy, Reconstruction, and Jim Crow laws. The South was also the location for the research. Therefore, much attention is given to abuses that occurred in this locale. Furthermore, the intent of this summary is to show the pattern of medical abuses and to provide a historical context for the study.

Historical context is important to understand because past abuses by the healthcare system continue to shape African American ESRD patients' view of the medical system, as mentioned previously (Kennedy, Mathis, & Woods, 2007; Nelson, 2011; Washington, 2006). In addition to historical context, the following will be addressed in the next chapter: the disease context of ESRD, a discussion of the uniqueness of ESRD, a review of the literature concerning the current racial inequities in the healthcare system, medication adherence and chronic disease, and racial inequality and medication adherence in the ESRD population.

CHAPTER 2

LITERATURE REVIEW

Historical Racial Inequities in Healthcare

Slavery. The current racial inequities in the healthcare system are the result of a centuries-long history in which African Americans have been subjected to unequal, unethical, and torturous medical treatment and experimentation (Byrd & Clayton, 2000; Smith, 1999; Washington, 2006). This history began even before the first slaves arrived in the English colonies in 1619 (Byrd & Clayton, 2000; Washington, 2006).

During the Atlantic slave trade, slaves were often kidnapped from the interior of Africa and brought to the Western coast of Africa to board slave ships. Before boarding, slaves were physically examined to determine their purchasing worth, their “soundness” (Fett, 2002, p.18). Medical doctors were employed by slave ship owners to conduct these inspections at a wage second only to the ship’s captain (Byrd & Clayton, 2000; Fett, 2002). Once on the slave ship, however, most doctors did little to ameliorate the devastating and brutal conditions slaves experienced during the voyage. Slaves were, “...shackled and stacked like spoons on shelves” (Byrd & Clayton, 2000, p. 195). They were often starved, given stagnant water, and were forced to live in their own urine and feces throughout the Middle Passage. The mortality rate was high ranging from 15 to 80 percent (Byrd & Clayton, 2000). Although germ theory did not exist in the 17th century, doctors did know that clean water, adequate food, and sanitation practices were essential

to health (Blanton, 1972). However, historical records indicate that doctors did not intervene to improve slave ship conditions (Byrd & Clayton, 2000). Therefore, the vast majority of slaves that did survive the Middle Passage arrived in the New World in poor health (Blanton, 1972; Byrd & Clayton, 2000).

Beginning in 1735 with Linnaeus' classification of humans in *System Naturae*, Blacks were scientifically classified as an inferior race (Gould, 1996). This idea soon suffused medical science throughout the world including the burgeoning US. The bodies of slaves were considered different from and inferior to White bodies (Downs, 2012; Gould, 1996; Lock & Nguyen, 2010; Quraishi & Philburn, 2015; Roberts, 1997). Medical science concluded through experiments and anatomical exploration steeped in racist ideology that African Americans compared to Whites had smaller brains (Bean, 1906), felt less pain, were less resistant to disease, were lascivious (Johnson & Bond, 1934), and had "lower mental faculties" (Bean, 1906, p. 411). An example of such sentiment is Van Evrie's, a medical doctor, (1868) claim that African Americans were so anatomically and intellectually inferior to Whites that any attempt to educate them would result in the inability of African Americans to walk upright. Van Evrie (1868) stated,

On the contrary, the narrow and longitudinal head of the Negro projecting posteriorally (*sic*) places his eyes at an angle with the horizon, and thus alone enables him to approximate to an erect position. Of course, we are not to speculate on what is impossible or to suggest what might happen if the Negro head had resembled that of the Caucasian, for the slightest change of an elementary atom in the Negro structure would render him an impossible monstrosity. But with the broad forehead and small cerebellum of the White man, it is perfectly obvious that the Negro would no longer

possess a center of gravity, and therefore those philanthropic people who would "educate" him into intellectual equality or change the mental organism of the Negro, would simply render him incapable of standing on his feet (p. 93-94).

During the 17th, 18th, and 19th centuries, the slave trade and plantation economy flourished in the South. By 1860 there were four million slaves in the US (Washington, 2006), 90% of whom were located in the most unhealthy region of the US, the South (Washington, 2006). Disease was endemic to the South and medical science was nascent in the 19th century. However, White plantation owners fared much better than their slaves (Savitt, 2002; Washington, 2006). Slaves were often worked to exhaustion, physically and emotionally abused, raped, poorly housed, and often starved (Savitt, 2002; Washington, 2006). Additionally, since physician services were expensive, medical care was a last resort (Fisher, 1968; Savitt, 2002; Washington, 2006). Physicians sometimes complained of the harsh conditions slaves endured, but many kept quiet because they were dependent on the financial relationship with the slave owners (Byrd & Clayton, 2000; Washington, 2006). Physicians commonly contracted their services to plantation owners for the care of slaves (Byrd & Clayton, 2000; Washington, 2006). Thus, plantation owners were regarded as the clients as opposed to the enslaved (Byrd & Clayton, 2000). Therefore, most physicians were complicit in the subjugation of enslaved African Americans because to do otherwise would result in financial insecurity. For example, slave owners often assumed that any sickness was fabricated to enable slaves to "malingering" (Washington, 2008, p. 30). Slavers relied on doctors to confirm this assumption. As a result, doctors sometimes administered caustic chemicals to punish slaves complaining of illness or suggested such "medicine" as whipping (Fett, 2002).

Since slaves were regarded as inferior and biologically different from Whites by the medical community at the time, especially in the South, “Negro Medicine” was born (Byrd & Clayton, 2000; Savitt, 2002). Physicians in the South, adherent to Linnaeus’ theory of race, catalogued “racial traits” that were based on biblical interpretations, personal aversion to African Americans, and mythology and called it science (Byrd & Clayton, 2000). Once African Americans were defined “scientifically” as separate from and less than Whites, the next step was professionally sanctioned medical experimentation (Fauci, 2001; Jones, 1993; Washington, 2006). African American slaves were the victims of experimentation, which included investigating the effects of ether, practicing gynecological surgical techniques, pouring boiling water on their spinal columns, and leaving them in open pits in the heat of the day to see if new medications enabled them to withstand excessive temperatures (Fauci, 2001). In addition, Southern medical schools advertised that students would have ample opportunity to study disease, hone surgical skills, and obtain anatomical knowledge for their future medical practice due to the availability of slave patients and slave cadavers (Fett, 2002; Washington, 2006).

Such institutionalized and racist ideology led to African American bodies being used as objects to test medicines, to practice medical procedures, and to practice surgeries even if there were no therapeutic justifications for such actions (Nelson, 2011; Washington, 2006). The purpose of medical interventions often was to provide information and perfect skills that could be used to treat White patients (Fett, 2002; Washington, 2006).

Emancipation. After the slave economy in the South was abolished, many newly freed slaves were banished from their plantation homes with nowhere to go. Some found shelter in refugee camps with little food and deplorable sanitation conditions. It is estimated that between 25% and 33% of freed slaves died during the first years of Reconstruction (Morais, 1967). However, the federal government's response to this unprecedented suffering was to focus on finding employment opportunities for the freed slaves (Downs, 2012). The prevailing thought was that if freed slaves had jobs, then food and better living conditions would lead to better health.

The Freedmen's Bureau was established by the War Department to find such opportunities. With no existing infrastructure to accommodate freed people in the South and a resentful White power structure unwilling to provide assistance, the Freedmen's Bureau made deals with existing plantation owners referred to as contract/lease arrangements. The federal government contracted with plantation owners to lease freed slaves to the land owners. The result was that many freed slaves were forcibly taken from refugee camps and placed back on plantations. The plantation owners agreed to house and feed some former slaves in exchange for work. When this occurred, plantation owners were loath to provide any services to their new "employees" beyond meager food and shelter for their work (Berlin, Glymph, Miller, Reidy, Rowland & Saville, 1990). Healthcare in any form was no longer a concern for plantation owners (Downs, 2012). Those who could not find work, often women and children, were left homeless, starving, and dying of disease (Downs, 2012). In addition, hospitals refused to care for the newly emancipated (Savitt, 2002). Instead, African Americans were left only to their own indigenous folk healing remedies (Downs, 2012; Fett, 2000).

Eventually, because African Americans continued to be excluded from the healthcare system, the Freedmen's Bureau constructed ninety hospitals to serve African Americans in the South (Byrd & Clayton, 2000; Fauci, 2001). However, these hospitals were often of little help besides providing temporary food and shelter. Some hospitals had a limited supply of medication and few resources to care for the disease epidemics that occurred during Reconstruction. Even those freed people with jobs could not afford medical care such as vaccinations for preventable diseases such as smallpox.

In addition, many physicians and White Southerners blamed the former slaves for disease epidemics citing the prevailing belief that African Americans were inferior biologically (Byrd & Clayton, 2000; Downs, 2012; Fett, 2002; Jones, 1993). As an example, during the smallpox epidemic from 1862-1868 many African Americans did not seek help and hid those family members who were sick because they were labeled as shameful vectors of disease (Downs, 2012). Furthermore, there was a fear of the newly emancipated that their disease would simply be studied and not ameliorated. Some feared that, "doctors would visit sick former slaves in the name of a so-called cure, but were actually motivated by a prurient fascination to observe how smallpox erupted on Black skin" (Downs, 2012, p.97). The smallpox epidemic overwhelmed the Freedmen's Bureau hospitals, and accurate records were not kept. However, as an example of the devastation of the disease, at the height of the epidemic in 1865, 30,000 former slaves died in a six-month period in the Carolinas alone (Downs, 2012).

Reconstruction ended in 1877. Republican presidential candidate, Rutherford B. Hayes, told Southern congressional Democrats that if he were elected president, he would end Reconstruction. Thus, in exchange for their support, he promised to pull out federal

troops from the South. A deal was struck. Hayes was elected President and a new era began in the South, Jim Crow. With the federal troops gone from the South, White supremacy reigned, and African Americans were subjected again to abuse, disenfranchisement, societal exclusion, and death. Lynchings became societal events (Allen & Lewis, 2000; Washington, 2006). They were sometimes published as upcoming events where families gathered to picnic and watch the execution (Allen & Lewis, 2000; Ginzburg, 1996). Families took pictures and sent them as postcards to friends and relatives of the lynching they attended. It was such a frequent occurrence that the US Postal System eventually banned the mailing of such postcards in 1908 (Allen & Lewis, 2000). The following is a discussion of the medical abuses during Jim Crow.

Jim Crow. During the Jim Crow Era, overt racism remained prevalent in the US. African Americans were not permitted in most hospitals in the South and were separated from Whites in hospitals in the North (Fauci, 2001; Washington, 2006). Medical experimentation also continued (Byrd & Clayton, 2000; Smith, 1999; Washington, 2006). Aubre Maynard, a surgeon at Harlem Hospital, commented on the treatment of African Americans by the healthcare system in 1926 (as cited in Smith, 1999):

As the helpless slave, as the impoverished freedman following emancipation, as the indigent ghetto resident of today, the share-cropper or dirt farmer of the South, the Negro has always been appropriated as choice “clinical material” by the medical profession. In the mind of the unregenerate racist, who, unfortunately, has always been represented in the profession the Negro was always next in line beyond the experimental animal. Without his fate subject to the quality of their skill, and the integrity of their character He has sometimes benefited from their efforts, but he has

also occupied the role of victim and expendable guinea pig. (p. 24)

It is during this time period that one of the most infamous healthcare and medical research abuses in US history began, the Tuskegee Syphilis Study. The study was conducted by the United States Public Health System (USPHS). The purpose of the study, which began in 1932, was to ascertain the progression of untreated syphilis in African American men living in Macon County, Alabama (Brandt, 1978; Jones, 1991). None of the men in the study were informed that they had syphilis until the study was stopped in 1972. In addition, none of the men were ever treated for syphilis even when there was an affordable and effective treatment. Instead, they were studied so that doctors could determine how syphilis manifested in the bodies of African Americans. Syphilis was considered the new scourge on African Americans, a scourge for which they were once again to blame.

During Jim Crow, physicians referred to syphilis as the new epidemic plaguing African Americans. African Americans were referred to by the medical community as, “a notoriously syphilis-soaked race” (Jones, 1993, p. 27). As with the other disease epidemics, African Americans were blamed for the spread of the disease and thought to be especially prone to the disease. Since syphilis is a sexually transmitted disease, the long-held belief in the medical community that African Americans were morally corrupt and licentious reemerged as an explanation for the occurrence of the deadly disease (Brant, 1978; McHatton, 1906). This idea was also coupled with the belief that African Americans were impossible to medically treat for syphilis. This sentiment was expressed by Dr. Murrell in 1906,

Even among the educated, only a very few will carry out the most elementary

instruction as to personal hygiene. One thing you cannot do, and that is to convince the negro that he has a disease that he cannot see or feel. This is due to lack of concentration rather than lack of faith; even if he does believe, he does not care; a child of fancy, the sensations of the passing hour are his only guides to the future (as cited in Brandt, 1978, p. 28).

Thus it is within this social and medical context that the Tuskegee Study began.

According to Smith (1999), this context led to three racialized assumptions which guided and justified the study. First, physicians continued to view African Americans as biologically different from Whites. Thus the prevailing thought was that syphilis affected the two races differently. Second, the men were poor, Black, and uneducated; therefore, the assumption was that they would not comply with the complex treatment regimen. Third, because the men did not have access to medical care, it was assumed that participating in this study was better than having no care at all (Smith, 1999).

Included in the study were 399 Black men whom researchers knew had been infected with syphilis before the experiment. In addition, 201 Black men who tested negative for syphilis were included as the control group (Brandt, 1997; Jones, 1993). However, the researchers never informed the men that they had been tested for syphilis or that they had tested positive or negative for the disease. Instead the men were told they were being treated for “bad blood” and would receive free medical care, transportation to and from medical appointments, hot meals on the day of medical appointments, and paid burial expenses (Brandt, 1978; Jones, 1993).

In addition to never informing the infected men that they had syphilis, the researchers

consistently lied to the men to ensure that they remained in the study and the maximum amount of data could be collected on the progression of the disease. For example, to make sure the men showed up for such painful tests as spinal taps, researchers told them they were receiving “special free treatment” (Jones, 1993, p.113). In addition, the men who expected some type of treatment as they were promised were given doses of mercurial ointment and neoarsphenamine, which were known to be ineffectual, instead of the medically accepted drugs of treatment in 1932, arsphenamine and bismuth (Jones, 1993). As the chief physician of the study, Vonderlehr, who was overseeing the administration of the ineffectual drugs and tonics, maintained he feared the men would not continue to agree to the study if they did not receive some type of treatment. He stated,

Expenditure of several hundred dollars for drugs for these men would be well worth while if their interest and cooperation would be maintained in doing so....It is my desire to keep the main purpose of the work from the negroes in the county and continue their interest in treatment. That is what the vast majority wants and the examination seems relatively unimportant to them in comparison. It would probably cause the entire experiment to collapse if the clinics were stopped before the work is completed (as cited in Brandt, 1978, p.24).

In addition to gaining information from spinal taps, the research team believed that only through autopsies could they gain definitive data about the effects of syphilis on African Americans. The researchers realized that autopsies were not deemed culturally acceptable by African Americans living in Macon County, Alabama. As the consultant to the study, Dr. Wegner, wrote to Vonderlehr in 1933,

There is one danger in the latter plan and that is if the colored population become aware that accepting free hospital care means a post-mortem, every darkey will leave, Macon County and it will hurt Dibble's (hospital director) hospital (as cited in Jones, 1993, p.134).

So the researchers decided that the men would have to die in the hospital and surreptitiously be autopsied (Jones, 1993). The researchers reasoned that since the men trusted the United States Public Health Service, they would trust Dr. Dibble. Dr. Dibble was the Director of the Tuskegee Institute Hospital and newly appointed to the USPHS. He was a government doctor, so the men and their families would not be suspicious. As an added incentive, the USPHS offered to pay for the men's burials if they died in the hospital (Jones, 1993).

Once it was discovered that penicillin was a successful treatment for syphilis in 1947, treatment was withheld from the men. Throughout the experiment, findings were published several times in medical journals (Olansky, Simpson & Schuman, 1954; Rockwell et al., 1964; Shafer, Usilton & Gleeson 1954). However, the experiment was not stopped or investigated for withholding treatment. This is significant since during the 40 years of the experiment strides were made nationally and internationally to protect human rights especially for research participants. For example, after the medical atrocities of the Holocaust, the Nuremberg Code was adopted to protect research participants from being forced into experimentation against their will (Mitscherlich & Mielke, 2010). In addition, the Declaration of Helsinki by the World Medical Association (1964) mandated that research participants must give informed consent. Furthermore, the USPHS blocked any attempts to medically treat the men with syphilis

(Brandt, 1978; Jones, 1993). For example, the Alabama Health Department began a campaign in the 1940s to end venereal disease throughout the state. The agency sent medical mobile vans into the rural counties to test and administer medication for venereal diseases. The USPHS told the Alabama Health Department that they were not allowed to test or treat the syphilitic men in the Tuskegee Study (Brandt, 1978). As another example, during WWII many of the syphilitic men were drafted. The men were tested and told to begin treatment. The USPHS intervened. They explained that the men were part of a longitudinal study and asked that they remain untreated. The draft board agreed and no treatment was administered (Brandt, 1978).

The Tuskegee experiment abruptly ended in 1972 when a psychiatric social worker, Peter Buxtun, who worked for the USPHS informed an Associated Press journalist of the experiment. The information was passed to Jean Heller, a journalist, and published in the *Washington Star* on July 25, 1972 (Jones, 1993, Brandt, 1978). The Tuskegee researchers defended the experiment while the federal government called for an internal investigation of the USPHS. Eventually, due to public outcry, the government assembled a nine-member ad hoc panel which gave their results to the Department of Health, Education, and Welfare. The Panel concluded that the study was unethical and the men should have been treated with penicillin in the 1940s (Brandt, 1978). However, there was no mention of the basic premise of the experiment, to deny treatment. As a result of the study, 128 men died of syphilis and related complications according to physical examinations and autopsies (Jones, 1993; Washington, 2006). It is important to understand the Tuskegee Syphilis Study because for many African Americans it has become, “a symbol of their mistreatment by the medical establishment” (Kennedy,

Mathis & Woods, 2007, p. 56). A symbol of racism within the healthcare system that has been cited by some researchers as one reason for African Americans' high levels of distrust of the healthcare system (Hammond, 2010; Jones, 1993; Kennedy, Mathis & Woods, 2007; Shavers, Lynch & Burmeister, 2000). Thus, since this study is examining if everyday racism plays a role in medication nonadherence, understanding the impact of past medical abuses endured by African Americans especially as significant and well-known as the Tuskegee Study is essential.

It was also during the Jim Crow Era that the first artificial kidney was invented (Friedman, 1998). Today most patients diagnosed with ESRD are eligible for Medicare. ESRD is one of only two chronic diseases (Amyotrophic Lateral Sclerosis is the other) that are guaranteed Medicare coverage. Most persons diagnosed with ESRD have access to dialysis only because their dialysis costs are covered through Medicare (Medicare, 2011). This coverage has not always been provided. When the process of dialysis was invented, it was viewed as experimental and funded primarily through donations and the private funds of patients (Browne, 2012; Peitzman, 2001). There were many more ESRD patients needing treatment than available dialysis machines or funds to pay for treatment expenses. As a result, dialysis was rationed. Rationing is the allocation of a needed, yet scarce, resource (Jonsen & Edwards, 2010). The end result of rationing is that some people receive the resource and others do not. In the case of kidney dialysis, treatment was allocated based on medical suitability and judged social worth of the patient. The following is a discussion of the history of dialysis and the impact of racial inequality.

Historical Racial Inequity & ESRD

Willem Kolff invented the first artificial kidney in 1943 that made dialysis possible (Friedman, 1998). The artificial kidney unit was expensive to produce and maintain, thus few were created (Friedman, 1998). The artificial kidney required physical access to the circulatory systems of patients (Friedman, 1998). Thus, patients were surgically connected to the artificial kidney. Surgical connections were only feasible for short-term use due to the possibility of surgical wound infections (Friedman, 1998). Given these constraints, Kolff and the medical community envisioned the artificial kidney as only useful for patients suffering from acute renal failure who would recover with a few treatment sessions and had the ability to pay for the expensive treatment (Friedman, 1998). Hence, African Americans, who were relegated to substandard medical care during this time period, if they were provided care at all, were not considered for treatment.

In 1960, Scribner revolutionized kidney dialysis with his invention of the dialysis shunt (Peitzman, 2001). The shunt was a device surgically inserted under the skin of the forearm which allowed constant access to patients' circulatory systems (Peitzman, 2001). This technological advancement meant that dialysis could be offered to patients with chronic kidney disease on an outpatient basis. However, dialysis was still quite expensive. In the early 1960s, the cost of dialysis was \$15,000 per person per year (Fetherstonhaugh, 2009). Scribner obtained funding from the Hartford Foundation and began offering community dialysis through the Seattle Artificial Kidney Center (SAKC) in 1962 (Peitzman, 2001). The SAKC was the pioneer community dialysis center. Upon opening, the SAKC was inundated with ESRD disease patients in need of dialysis. In the

early 1960s, it was estimated that 40,000 people were dying a year from ESRD (Fetherstonhaugh, 2009). To choose who would receive dialysis, Scribner and his colleagues devised a two-tiered patient selection system. The first tier of the selection process was based on the following criteria:

They had to be stable, emotionally mature, uremic adults under the age of 45, without long-standing hypertension and vascular complications, willing to cooperate with the dialysis regimen and low protein/low sodium dietary regimen, and with stable or slowly deteriorating renal function (Blagg, 2007, p. 485).

The medical criteria also included a psychological assessment to ascertain if the patient had the ability to "...take an active role in their own well-being; have the potential for rehabilitation" (Fetherstonhaugh, 2009, p.89). Rehabilitation was defined by the doctors as having the potential to be a productive citizen and live a "useful life" (Fetherstonhaugh, 2009, p.89). Furthermore, young adults who could not financially support themselves were rejected. Children were not considered candidates for dialysis for two reasons. First, the procedure presented too many complications with children, and Scribner and his colleagues wanted those patients with the best chances of survival to receive dialysis (Blagg, 2007). Second, those at SAKC making the selection decisions thought it unfair to allow a child to receive dialysis and deny dialysis to a patient who was the head of a household consisting of many children (McGough, Reynolds, Quinn, & Zenilman, 2005).

The second tier of the selection process involved the Admissions and Policies Committee. This was an anonymous committee comprised of seven community members that included, "...lawyer, a minister, a banker, a housewife, an official of state

government, a labor leader and a surgeon” (Alexander, 1962, p. 107). The committee members were also described as being White, Protestant, middle class citizens (McGough et al., 2005). The task of the committee was to make final patient selection decisions. The committee based their decisions on many patient factors including level of education, marital status, net worth, work performance and history, and number of dependents (McGough et al., 2005). The committee selected patients who they thought had the most promising potential to remain, or soon become, productive community members (McGough et al., 2005). The committee based their decisions on how important they thought each applicant was to the community (McGough et al., 2005). In other words, they used social worth as their standard of measure.

For the committee members, social worth was narrowly defined by their Protestant, White, middle-class value system. This is evidenced by the patients that they chose to receive dialysis. The committee overwhelmingly chose men who were White, married with many children, active in church and the community, had a history of positive performance at work, and were middle class to receive dialysis (Blagg, 2007; Fetherstonhaugh, 2009; McGough et al., 2005). No African American was chosen for dialysis during this time even though they were a growing segment of Seattle’s population (Peitzman, 2001; Seattle Municipal Archives, 2016). After World War II many African Americans moved North and West in search of employment, and Seattle was a popular destination (Seattle Municipal Archives, 2016). The African American population in Seattle increased from 1% in 1940 to 4.8% in 1960 (Seattle Municipal Archives, 2016). Lastly, it is important to keep in mind that those who were not chosen for dialysis, those who did not correspond to the committee’s values, died.

Months after the SAKC began providing outpatient dialysis, Shana Alexander (1962) wrote an article for *Life* magazine (Blagg, 2007). In the article, she described SAKC's mechanism for dialysis allocation. The public was appalled that patients were selected to live because of their apparent usefulness to society (Blagg, 2007). Interestingly, the medical criteria, although scrutinized today, was considered at inception to be value-free and without bias. The outrage that ensued focused on the fact that women, children, and older adults were not eligible for dialysis given the social worth criteria (Blagg, 2007). However, there was no documented outrage that no African American had received dialysis (Peitzman, 2001). Thus in 1972, women, children, and elders meant White women, White children, and White elders. On October 30, 1972, President Nixon signed the bill establishing the ESRD Medicare program (Blagg, 2007). This bill ensures that no ESRD patient can be denied dialysis based on inability to pay for services or social worth criteria. However, although dialysis cannot be denied to African American ESRD patients, racial inequities do presently exist within the ESRD population,

Dialysis and the current system of healthcare for ESRD patients takes place within the context of the biomedical model. The following is a discussion of this model and the current racial inequities that occur in the healthcare system and racial inequities as they pertain to medication adherence in the chronic disease population. Additionally, the uniqueness of ESRD as a disease, the extraordinary burden of medication adherence within this population, and the current racial inequity in the medication adherence of ESRD patients will be examined.

The Biomedical Model

Today, hemodialysis and medication adherence are medical treatments that occur within the parameters of the prevailing model of medicine in the US, the biomedical model. The biomedical model privileges the technical understanding of the pathology of disease and its effects on patient physiology (Annadale, 1998; Wade & Halligan, 2004). The anatomical body is separated from the social and psychological body and subjected to scientific examination (Annadale, 1998; Wade & Halligan, 2004). Thus, the medical provider is the expert who prescribes treatments and medication to be absorbed by patients with little input or inquiry from patients (Mykhalovskiy, McCoy, & Bresalier, 2004).

In addition, when patients do not take their medication as directed, medical providers often engage in repressive attempts to cajole or scare patients into following their directions (Mykhalovskiy, McCoy, & Bresalier, 2004). Accordingly, patients are effectively silenced. This model is particularly salient to African American consumers of healthcare. As discussed earlier, for centuries African Americans have been subjected to a racialized healthcare system (Byrd & Clayton, 2000; Fisher, 1968; Nelson, 2011; Savitt, 2002; Smith, 1999; Washington, 2006). However, the racial inequities within the biomedical structure of healthcare provision are not simply reserved for the past. Today, racial inequities of care continue. The following is a discussion of the current unequal medical treatment of African Americans within the racialized context of healthcare in the US.

Current Racial Inequities in Healthcare

Research suggests that patients' race and ethnicity influences physicians' diagnostic evaluations and treatment decisions, as well as their feelings about patients (Green, 2007; Smedley, Stith, & Nelson, 2002; US Department of Health and Human Services, 2014; Van Ryn & Burke, 2000). For example, Green and colleagues (2007) found in their study of 220 physicians that physicians' implicit bias was associated with differences in treatment recommendations for patients presenting with myocardial infarctions. In addition, Van Ryn and Burke (2000) conducted a study of physicians' perceptions of post-angiogram patients. The study involved 193 physicians who reported on 618 patient encounters. The authors found that patient ethnicity was associated with a number of negative assessments of patients. Specifically physicians rated African American patients as less intelligent, more likely to engage in risky behaviors, less educated, less likely to adhere to medical advice, and less likely for physicians to feel affiliation towards compared to White patients (Van Ryn & Burke, 2000). Similarly, the 2014 National Healthcare Disparities Report indicates that White patients receive better quality of healthcare than African Americans patients (US Department of Health and Human Services, 2014).

Studies also show that African Americans are aware of the racial biases of healthcare providers and report racial discrimination occurring in interactions within the healthcare system more than Whites (Hausmann, Jeong, Bost, & Ibrahim, 2008; Hausmann, Kressin, Hausa, & Ibrahim, 2010; LaVeist, Nickerson & Bowie, 2000; Peek, Wagner, Tang, Baker & Chin, 2011; Shavers et al., 2012; Sorkin, Ngo-Metzger, & De Alba, 2010). For example, LaVeist, Nickerson and Bowie (2000) found in a sample of 1,784 cardiac

patients that 30% of African American patients reported that racial discrimination in a doctor's office is common compared to 7.3% of Whites. Another study found that 10.9% of African Americans reported perceived racial discrimination in the healthcare system compared to 2% of Whites (Hausmann, Jeong, Bost, & Ibrahim, 2008).

Thus, the experience of current racial discrimination coupled with a centuries-old history of invidious medical abuses is postulated to lead to distrust of the healthcare system among African Americans (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Freedman, 1998; Kennedy, Mathis, & Woods, 2007; LaVeist, Nickerson & Bowie, 2000; LaVeist, Morgan, Arthur, Plantholt, & Rubinstein, 2002). For example, Freedman (1998) conducted a qualitative study with 13 African American women and found that the participants worried that their certain health issues were "often over-looked by White physicians" (p.943). Kennedy, Mathis, and Woods (2007) echo this sentiment stating, "Distrust of the health care system by African Americans runs from the feelings of ill gains for participation in clinical trials to being used only as guinea pigs" (p. 57). Furthermore, distrust of the healthcare system because of racism has been linked to less utilization of medication (Finnegan et al., 2000; Fiscella, Franks, Gold, & Clancy, 2000; LaVeist, Nickerson, & Bowie, 2000; Paradies, 2006; Van Houtven et al., 2005).

Racial Inequity, Medication Adherence and Chronic Disease

There is a large literature base regarding medication adherence and chronic disease with evidence that African Americans exhibit low medication adherence (Barton, 2009; Halkitis, Palama, & Mukherjee, 2008; Shenolikar, Balkrishnan, Camancho, Whitmire, & Anderson, 2006). For example, Shenolikar, Balkrishnan, Camancho, Whitmire, and Anderson (2006) conducted a study to ascertain levels of medication adherence in a

sample of participants who were diabetic. The authors found that the rates for adherence to diabetic medications were 12% lower for African Americans compared to Whites (Shenolikar, Balkrishnan, Camancho, Whitmire, and Anderson, 2006). Similarly, Halkitis, Palmar, and Mukherjee (2008) found that African American men were less adherent to their antiretroviral medication regimen than Hispanic and White men in their study. Although these studies measured medication self-management, they did not examine the possibility that perceived racism contributes to the lower adherence rates in their samples.

Additionally, there are a few studies that have shown a link between racial discrimination experiences and medication adherence with patients diagnosed with diabetes (Bhattacharya, 2012; Dawson, Walker, Campbell & Egede, 2015), hypertension (Cuffee et al., 2013; Forsyth, Schoenthaler, Chaplin, Ogedegbe & Ravenell, 2014; Lewis, Askie, Randleman & Shelton-Dunston, 2010; Lukoschek, 2003), and HIV (Moore, Stanton, Gopalan, & Chaisson, 1994; Shapiro et al., 1999; Siegel, Karus & Schrimshaw, 2000). For example, Kressin et al. (2010) showed in their sample of 806 hypertensive African Americans that those who reported more racial discrimination experiences were less adherent to their hypertensive medication regimen. Similarly, Cuffee et al. (2013) found that perceived racial discrimination was associated with lower medication adherence in their sample of 780 African American men and women with hypertension. Lastly, in a study of 134 hypertensive African American men and women, the author found a negative association between high levels of perceived racism and medication adherence (Daramola, 2009).

However, there are few medication adherence studies of patients with ESRD and even fewer studies that have measured medication adherence in the African American population (Curtin, Svarstad, Andress, Keller, & Sacksteader, 1997; Curtin, Svarstad, & Keller, 1999; Leggat et al., 1998; Saran et al., 2003). Additionally, no studies have examined the possible influence of everyday racism on medication nonadherence. This is troubling since the results of medication nonadherence for ESRD patients are increased hospitalizations (Saran et al., 2003; USRDS, 2015), decreased quality of life (USRDS, 2015), increased morbidity (USRDS, 2015), and death (Browne, 2012; Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte, & De Geest, 2007).

Uniqueness of ESRD

ESRD is a uniquely burdensome disease. ESRD has profound negative effects on many organ systems, results in high rates of mortality and hospitalization, and is costly. With the failure of the kidneys, many systems in the body are affected leading to an array of physical ailments. ESRD patients may suffer from bone fractures and pain, anemia, high blood pressure, neuropathy, blood glucose problems, cardiovascular problems, liver failure, congestive heart failure, hyperparathyroidism, increased risk of infections, malnutrition, muscle pain, dementia and brain dysfunction, stomach and intestinal bleeding, electrolyte imbalance, and seizures (Brenner, 2008). For many ESRD patients, fluid can leak from the pores in their skin and crystallize causing unremittingly itchy skin and infections (Berger & Steinhoff, 2011). Others cannot get relief from restless legs (Gigli et al., 2004), and some experience such extreme fatigue that getting out of bed is a challenge (Jhamb, Weisbord, Steel & Unruh, 2008).

Given the severe effects of ESRD, dialysis patients have significantly higher mortality and fewer expected remaining life years than the general population. The average life expectancy for a person on dialysis is five to ten years after initial diagnosis (NKF, 2016). Dialysis patients younger than 80 years old have a life expectancy less than one third as long as those without ESRD (USRDS, 2015). Furthermore, ESRD patients 80 years old and older have a life expectancy less than one half as long as those without ESRD (USRDS, 2015). ESRD patients in general also have significantly higher mortality rates than other Medicare populations with chronic diseases such as diabetes, cancer, or cardiovascular disease (USRDS, 2015). For example, mortality rates for ESRD are 1.7 times higher than heart failure patients and 4 times higher than diabetic patients (USRDS, 2015). Lastly, there are ethnic differences in mortality rates. African American and White ESRD patients younger than 45 years old have similar mortality rates. However, older White ESRD patients have higher mortality rates compared to African Americans.

ESRD patients also suffer high rates of hospitalization for many reasons including vascular access, infections, and cardiac events. ESRD patients must endure many procedures to achieve vascular access for dialysis. A catheter, arteriovenous (AV) fistula, or AV graft provides vascular access. African Americans overwhelmingly choose AV fistulas (Iacono, 2004). Unfortunately, there is a 35.9% failure rate for AV fistulas with African Americans experiencing the highest failure rates (Dember et. al., 2014). ESRD patients are also hospitalized nearly two times a year for a total of 11.2 days per patient year (USRDS, 2015). Furthermore, when ESRD patients are compared to Medicare patients who do not have ESRD, those with kidney failure are hospitalized

more than twice as much. Lastly, African Americans experience higher rates of readmission to the hospital and death within 30 days of hospital discharge compared to Whites.

In addition to the burdens suffered by individuals with ESRD, there are profound monetary costs involved for society. The annual cost incurred by Medicare for ESRD patient care is \$29 billion (USRDS, 2015). To put that in perspective, total Medicare spending was \$618.7 billion in 2014 (Center for Medicare and Medicaid Services, 2014). Moreover, Medicare spends \$70,000 on average for each ESRD patient compared to \$9,523 spent on average for each Medicare recipient without ESRD (Center for Medicare and Medicaid Services, 2014). Therefore, a significant portion of Medicare is allocated to less than 1.3% of Medicare recipients. Furthermore, as mentioned above, ESRD patients experience frequent hospitalizations. Hospitalizations of ESRD patients account for 40% of the entire Medicare budget for ESRD patients (Center for Medicare and Medicaid Services, 2014; USRDS, 2015).

ESRD is a debilitating chronic disease that poses an extraordinary burden for patients both individually and societally irrespective of race. However, there is evidence of racial disparities in quality of care and access to care for patients with ESRD. The following is an explication of the unique burdens of ESRD and evidence of racial disparities.

Burdens of ESRD & Medication Adherence

Medication adherence is uniquely challenging for ESRD patients. ESRD patients have the highest pill burden when compared to patients suffering from all other chronic diseases (Chiu et al., 2009). Due to the multiplicity of organ systems affected by ESRD, patients must take numerous types of medication. When the kidneys fail, the ability to

metabolize minerals is affected. Thus, myriad medications are needed to control phosphorous, calcium, and vitamin D (Brenner, 2008). Also, AV fistulas usually require multiple, painful surgeries and can result in chronic pain (Iacono, 2004). Sixty percent of ESRD patients suffer from chronic pain, which may lead to a decrease in quality of life (Iacono, 2004). Of ESRD patients with chronic pain 66% take prescription pain medication to control the pain, which adds another medication to an already complex regimen (Iacono, 2004).

On average, ESRD patients are required to take 6-12 pills per day; however, 25% of ESRD patients take 25 pills or more per day (Chiu et al., 2009; Schmid, Hartmann, & Schiffli, 2009). Also, pills are often difficult to swallow due to fluid restrictions, they often result in side effects such as nausea and vomiting, and some are extremely large in size (Chiu et al., 2009; Lindberg & Lindberg, 2008; Schmid, Hartmann, & Schiffli, 2009; Walker et al., 2006). Moreover, if laboratory results indicate that medication adherence is unsuccessful, ESRD patients may be prescribed more pills, further increasing their pill burden (Chiu et al., 2009). In addition to the sheer number of pills, negative side effects of the medication, and difficulty of ingesting pills, the medication regimen is complex. For example medication must be taken at different times throughout the day and are dependent on meals and fluid intake. Thus, it is difficult to establish a daily routine, and this complicates an already complex medication regimen.

Additionally, ESRD patients are often financially responsible for a portion of their medication expenses. ESRD patients' average out-of-pocket expense for medications per year is \$119 for patients with low income subsidy (LIS) and \$1,106 for those who do not have the subsidy (USRDS, 2015). This is higher than the general Medicare population

out-of-pocket cost, which ranges from \$105 for low income subsidy patients to \$590 for patients who do not qualify for a subsidy (USRDS, 2015). This can be a substantial hardship since patients often cannot work given treatment demands (Hirth, Greer, Albert, Young, & Piette, 2008).

In addition to the personal burden posed by medication, it is also costly to taxpayers. Since all ESRD patients are eligible for Medicare coverage when diagnosed, the majority (74%) of ESRD patients participate in the federal government's Medicare Part D Prescription Drug Coverage Plan (USRDS, 2015). For example, in 2013, per patient per year Medicare Part D spending for ESRD patients (\$6,673) was 2.6 times higher than for general Medicare patients (\$2,592) (USRDS, 2015).

In summary, the treatment for ESRD poses an extraordinary physical and monetary burden for patients irrespective of race. If patients do not adhere to treatment, the results include increased hospitalizations, morbidity, and death (Brenner, 2008; Browne, 2012). Thus given the gap in the literature regarding medication adherence amongst African American ESRD patients coupled with the unique burdens of ESRD, it is imperative to study the particular factors that influence medication adherence in this population.

Racial Inequity, Medication Adherence & ESRD

Few studies concerning ESRD patients have investigated the racial inequity in medication adherence. The majority of studies that have included ethnicity as a variable suggest that African American ESRD patients are less adherent compared to White ESRD patients (Curtin, Svarstad, Andress, Keller, & Sackstader, 1997; Curtin, Svarstad, & Keller, 1999; Leggat et al., 1998; Saran et al., 2003). For example, Leggat and colleagues (1998) found in their study of 6,251 hemodialysis patients that being African

American was a predictor of nonadherence. Furthermore, Curtin, Svarstad, and Keller (1999) found in their study of African American and White ESRD patients that only race/ethnicity was significantly associated with poor medication adherence. Specifically, 60% of African Americans were repeatedly nonadherent compared to 34% of Whites (Curtin, Svarstad, & Keller, 1999). Similarly, Saran et al. (2003) in their study of 8,396 ESRD patients found that African Americans were twice as likely as Whites to be nonadherent (Saran et al., 2003). Although, Curtin, Svarstad, & Keller (1999) and Saran et al., (2003) note that racism and discrimination may be a factor and urge researchers to study these constructs, no study has examined if perceived racial discrimination contributes to these disparities in medication adherence.

The following is a description of the methodology for the proposed research. To gain an understanding of the possible contribution of everyday racism to medication nonadherence, I use Critical Race Theory (CRT) as the theoretical foundation of the mixed methods study. CRT postulates that racism is endemic to US society and affects every aspect of society. I also propose to use the conceptualization of everyday racism by Essed (1991). Essed (1991) defines everyday racism as the manifestation of structural racism. The “everyday” is the context where the broader, structural racism occurs. Lastly, I will use both semi-structured, in-depth interviews and two scales, MARS-5 and DMS, to collect data. The qualitative portion of the study will be guided by CGT during data collection and analysis. For the quantitative portion, a correlations analysis will be conducted to ascertain if there is a relationship between the two constructs within the study sample.

CHAPTER 3

METHODOLOGY

The research study was reviewed and approved by the Institutional Review Board (IRB) at the University of South Carolina for Human Subjects approval before implementation.

Mixed-Methods Design

The research used a mixed-methods approach comprised of an exploratory qualitative study and a correlational quantitative study informed by Critical Race Theory to understand 1) if a statistical relationship existed between everyday racism and medication adherence and 2) how and to what extent everyday racism may have impacted the medication taking behavior of participants. This design was chosen because a gap in the literature currently exists regarding the racial medication adherence disparity within the ESRD population. The disparity in medication adherence within the African American ESRD population is a phenomenon of which little is known.

Additionally, no literature examines the possible role of everyday racism; therefore, a mixed methods study of the phenomenon enabled a more comprehensive exploration. This study used semi-structured, in-depth interviews and two surveys for data collection. For the qualitative portion, a Constructivist Grounded Theory was employed as the method for data analysis and development of theory. For the quantitative portion, Pearson's correlation analysis was conducted to ascertain if there was a statistical relationship between everyday racism in the healthcare setting and medication adherence.

The following is a discussion of sampling sites, recruitment, procedures, measures, and analyses methodology.

Sampling Sites

Currently, the vast majority of dialysis clinics in the US are owned by two large for-profit corporations, Fresenius Medical Care and DaVita (Sullivan, 2010). Since 1991, the for-profit dialysis industry has increased four-fold and dominates the healthcare market for those with ESRD (Sullivan, 2010). Given the corporate environment of dialysis clinics, it is quite difficult to obtain approval to conduct research on-site. Corporations usually cite patient confidentiality concerns and fear that the research will have negative implications for the company.

Due to the difficulty of conducting this study at dialysis clinics, African American ESRD patients who attended the National Kidney Foundation (NKF) Patient Empowerment Meeting (PEM) in North Carolina and South Carolina, and the American Association of Kidney Patients (AAKP) National Meeting in Tennessee comprised the sample. These events are designed for kidney dialysis patients and transplant patients across the South. The meetings offer kidney patients new information about kidney disease, dialysis, transplantation, the healthcare system, and dietary tips (NKF, 2016). Additionally, kidney patients can share their personal stories in a group forum and network with other kidney patients and kidney professionals (NKF, 2016).

These events were chosen as the setting for this study for three reasons. First, many members of the meetings are African American. Thus, there was a greater probability of obtaining enough interviews to reach saturation. Second, these meetings are independent of any dialysis clinic or dialysis corporation, and participants may be more willing to

discuss sensitive issues related to their dialysis clinic, pharmacy, and healthcare system if they are not being interviewed in such settings. Third, the meetings took place in the South, which is the area of interest for this study.

Recruitment

Convenience sampling was used at both conference locations. The researcher worked closely with the meeting organizers. The researcher made an announcement at the beginning of each meeting informing the attendees of the purpose of the research. Initially criterion sampling was used. Those participants who met the following inclusion criteria and agreed to participate were obtained for the study: 1) African American aged at least 18 years 2) Diagnosed with ESRD and on dialysis 3) Have physical stamina to engage in an interview 4) Speak English.

There are several reasons for the chosen inclusion criteria. First, participants in this study were African ESRD patients because of the focus of the research. Both females and males made up the sample. Second, participants were 18 years old and older. Children, those less than 18 years old, were not included in this study. ESRD is relatively rare in children as compared to adults. In addition, most children are not developmentally capable of independently adhering to a medication regimen. Therefore, parents or guardians are responsible for medication adherence in children. Hence if children were included this would be an entirely different study as I am interested in how racism in the healthcare system may influence medication taking behavior in African American ESRD hemodialysis patients. Although children with ESRD may experience and perceive racism in the healthcare system, they rarely are given the choice to make decisions to adhere or not. Instead, parents and guardians usually manage children's

medication taking. Third, ESRD is a severely debilitating disease, and a one- to two-hour interview can be exhausting for those without a chronic disease. Therefore, each participant was asked if she/he had the energy to be interviewed during the informed consent process. Fourth, the ability for each participant to speak English was a necessity, in that we chose to focus on English-speaking populations given limited funds for hiring an interpreter.

Procedures

In-depth interviews are defined as “a conversation with a purpose” (Kahn & Cannell, 1957, p.149). In-depth interviews were employed because they enabled the researcher to elicit participants’ beliefs, views, assumptions, and feelings in an effort to understand and explore the meaning that participants ascribed to everyday occurrences (Charmaz, 2006; Creswell, 2013). Furthermore, in-depth interviews allowed the researcher to obtain clarification of such meanings and to obtain a large amount of data in a relatively short amount of time (Marshall & Rossman. 1994).

Data were collected, transcribed, and analyzed using CGT methods of initial coding producing categories. These categories were elaborated through questioning, memo writing, comparison of categories, and deep thought. Data were gathered and analyzed until no new properties of the constructed categories emerged. At this point, the categories were considered saturated (Charmaz, 2006).

Twenty seven interviews were conducted lasting 20 minutes to approximately two hours. Theoretical saturation is difficult to predict before data collection begins and initial analysis occurs. Charmaz (2006) tentatively advises that 25 interviews may be sufficient. Creswell (2013) suggests 20 to 60 interviews may be sufficient. Ritchie,

Lewis, and Elam (2003) and Green and Thorogood (2009) propose that 20 interviews may be sufficient. Given the nebulous nature of theoretical saturation, the researcher worked closely with her committee chair and discussed theoretical insights, and when it seemed that collecting more data did not explicate constructed categories.

Data was collected using two surveys: MARS-5 and DMS scales (described below), a demographic questionnaire, and a series of interview prompts. The surveys were administered after the interviews to guard against priming the participants. Surveys were also available for participants who do not engage in the interviews. Interviews were recorded using an audio recorder and labeled numerically.

Measures

Demographic Survey. Sample characteristics measured included gender, age, level of education completed, type of insurance, and number of pills taken daily (see Appendix C).

Medication Adherence Reporting Scale. Medication adherence was measured quantitatively using the Medication Adherence Reporting Scale (MARS-5) (see Appendix A). The scale score was conceptualized as an ordinal variable which was analyzed at the scale level of measurement. MARS is a 5-item self-report scale which yields a single scale score ranging from 5 to 25. Each item is comprised of five points where *5=never*, *4=rarely*, *3=sometimes*, *2=often*, and *1=very often*. Higher scores indicate higher levels of self-reported adherence. The MARS has shown adequate reliability with a Cronbach's $\alpha = 0.85$ (Horne & Weinman, 2002). The measure has also been shown to exhibit construct validity as evidenced by a moderate correlation ($r=.53$) with an asthma drug count (Ohm & Aaronson 2006).

Discrimination in Medical Settings Scale. Everyday racism in the healthcare system was measured using the Discrimination in Medical Settings scale (DMS) (see Appendix B). The scale score was conceptualized as an ordinal variable which will be analyzed at the scale level of measurement. The DMS Scale is a 7-item self-report scale which yields a single scale score ranging from 7 to 35 (Peek, Nunez-Smith, Drum, & Lewis, 2011). Each item is comprised of five points where *5=always*, *4=most of the time*, *3=sometimes*, *2=rarely*, and *1=never* (Peek, Nunez-Smith, Drum, & Lewis, 2011). The Discrimination in Medical Settings (DMS) Scale exhibited good convergent validity as evidenced by significant positive correlations with the widely used Everyday Discrimination Scale (Peek, Nunez-Smith, Drum, & Lewis, 2011). The DMS Scale was not statistically associated with a measure of social desirability ($r=.18$, $p=.13$) thus establishing discriminant validity. In addition, the scale has a high degree of internal consistency (Cronbach's $\alpha=0.89$)(Peek, Nunez-Smith, Drum, & Lewis, 2011).

Qualitative Interview Prompts

To elicit the participants' lived experiences, the researcher asked probing questions and encouraged participants to share concrete examples of their struggles, if any, with everyday racism using the Interview Guide (see Appendix F). Interviews took place in a private room. The lengths of the interviews varied from 20 minutes to almost two hours depending on the participants' answers and the number of people interviewed together. All participants were asked permission to audio record interviews. None refused. Participants were given a \$25 incentive for participating in the interview process. Due to limited funds, no remuneration was given to those participants who only completed the survey.

In order to ensure confidentiality, the researcher assigned an identification number to each transcription. All interviews and transcriptions are kept on a password-protected computer. Any data in the form of hardcopies are secured in a locked storage file.

Analyses

Qualitative Data Analysis. The data management software NVivo 11 was used to code the data. The researcher analyzed the data using a CGT approach. Since the disparity in medication adherence within the African American ESRD population is a phenomenon about which little is known, CGT approach allowed for an in-depth understanding and iterative analysis of the data (Charmaz, 2006, 2011). CGT is steeped in the constructivist philosophical paradigm, which maintains that no objective reality exists (Charmaz, 2006; Denzin & Lincoln, 2011; Guba & Lincoln, 1994; Mertens, 2010; Schwandt, 1994). Instead, realities are subjective and are actively constructed through social interaction (Charmaz, 2006; Denzin & Lincoln, 2011; Guba & Lincoln, 1994; Mertens, 2010; Schwandt, 1994). Thus, individuals construct subjective meanings in order to understand their world. These subjective meanings are steeped in historical understandings and current interactions with others (Creswell, 2013). In the case of this research, everyday racism is also socially constructed. CRT maintains that race is a social construct that was historically produced as a tool to oppress in the form of racism (Delgado & Stefancic, 2012).

CGT data analysis includes collecting data, studying the data through memo writing, and coding the data (Charmaz, 2006). Coding is the process of constantly comparing the data and constructing conceptual categories that emerge through this comparison (Charmaz, 2006). In accordance with CGT methods, the data from the interview

transcripts, subsequent research memos, and reflexive journal were used to analyze the data into categories (Charmaz, 2006). According to CGT methods, coding occurs in two phases: initial coding and focused coding. The initial coding process was completed at a quick pace through a line by line examination of the data. After the initial coding was complete, the researcher began the process of focused coding. Focused coding involves finding the central codes and collapsing them and/or expanding them to make sense of the entire data set--in essence determining the major themes in the data. The researcher spoke to the Chair of her committee about thoughts and gleanings and spent much time thinking and questioning the generated categories. Codes were refined and merged and themes began to form. To avoid bias during qualitative analysis, both supporting and disproving examples pertaining to the relationship between racism and medication adherence were categorized. This process continued until data saturation occurred and theory was generated.

Quantitative Analyses. A negative relationship was hypothesized. It was hypothesized that African American ESRD patients who reported high incidences of everyday racism in the healthcare system would report lower adherence to their medication regimen. The null and alternative hypotheses are:

Ho: There is no statistically significant relationship between everyday racism in the healthcare system and medication adherence among African American ESRD patients.

Ha: There is a statistically significant negative relationship between everyday racism in the healthcare system and medication adherence among African American ESRD patients, thus $r < 0$.

In this one-tailed research hypothesis, everyday racism in the healthcare system is the independent variable, and medication adherence is the dependent variable. Since the hypothesis is concerned with ascertaining the relationship between the two variables, the statistical test chosen for analysis was the Pearson's correlation. The Pearson's correlation was chosen because it is used to determine the strength and direction of a linear relationship between two continuous variables. In this study the two variables are MARS-5 and DMS scale. The Pearson's correlation test generates a coefficient called the Pearson's correlation coefficient, r . The correlation coefficient measures the strength and direction of a linear relationship between two continuous variables. Its value can range from -1 for a perfect negative linear relationship to +1 for a perfect positive linear relationship (Tabachnick & Fidell, 2007). A value of 0 (zero) indicates no relationship between two variables. Prior to conducting the analysis, the level of significance was set at $\alpha = .05$. Therefore H_0 (the null hypothesis) will be rejected only if $p \leq .05$.

Data were entered into SPSS 24. Categorical data were coded using dummy variables while continuous data were entered verbatim. Frequency tables for all variables were generated to check for data input errors and missing data. There were few missing data and it appeared to be missing at random as opposed to a pattern of missingness.

CHAPTER 4

FINDINGS

The purpose of this study was to explore the possible relationship between everyday racism and medication adherence among African American ESRD patients. A mixed methods research study was conducted which was comprised of an exploratory qualitative study using constructivist grounded theory and a correlational quantitative study. Both methods were informed by Critical Race Theory. The specific aims of the qualitative study were to ascertain 1) Do African American ESRD patients experience everyday racism in the healthcare system? 2) If so, does everyday racism influence their medication adherence? 3) If so, in what way does everyday racism influence their medication adherence? 4) If not, what does influence their medication adherence? The specific aim of the quantitative study was to ascertain if there was a relationship between everyday racism in the healthcare system and medication adherence among a convenience sample of African American ESRD patients.

This chapter provides an overview of participants, then presents research findings in two parts. The qualitative portion of the study will be presented first followed by the quantitative portion of the study.

Participants

The total study sample included 46 participants (see Table 4.1). The semi-structured, in-depth interviews were conducted at two locations (AAKP, PEM) and a total of 27 African American ESRD patients were interviewed. After each qualitative interview,

each participant completed a quantitative questionnaire. Additionally, 19 participants completed the questionnaire who were not interviewed.

Table 4.1 Demographic and Descriptive Characteristics of All Participants (n=46)

Characteristics (range)	n(%)	Mean (SD)	Median
Gender			
Female	23(50.0)		
Male	23(50.0)		
Age			
		55.9(10.5)	55.0(44.0)
Education			
Some High School	8(18.2)		
Graduated High School/ GED	21(47.7)		
Graduated College (Bachelor's Degree)	13(29.5)		
Completed Graduate Studies (Master's or Doctorate Degree)	2(4.5)		
Insurance Primary			
Public Aid/Medicaid	9(20.5)		
State Renal Program	1(2.3)		
Medicare	30(68.2)		
Private Insurance	3(6.8)		
Federal Primary VA	1(2.3)		
Insurance Secondary			
Public Aid/Medicaid	3(6.8)		
State Renal Program	1(2.3)		
Medicare	3(6.8)		
Private Insurance	20(45.5)		
None Denoted	17(38.6)		
Daily Number of Pills			
		10.7(5.5)	10.0(19.0)

Fifty percent of the total sample is female and 50% is male. The average age of participants is 55.9 years. In addition 47.7% graduated high school or obtained their GED. This is followed by 29.5% graduated college and 18.2% reported having completed some high school, and 4.5% completed graduate studies. The primary mode of insurance for the sample is Medicare (68.2%), public aid/Medicaid (20.5%), private insurance (6.8%), state renal program (2.3%), and Federal Veteran's Administration (2.3%). Most participants indicated that private insurance (45.5%) served as their secondary mode of insurance. Additionally, 38.6% of participants did not denote a secondary mode of insurance. Participants stated that their secondary mode of insurance coverage was comprised of the following: Medicare (6.8%), Public aid/Medicaid (6.8%), and state renal program (2.3%). Lastly, the average daily number of pills was 10.7 (median=10.0; minimum=2; maximum=21).

Exploratory analyses indicated that the interviewed and non-interviewed groups did not differ on key variables including gender, age, education, insurance coverage type, and daily number of pills. The results of the one-way ANOVA do not show an overall significant difference between the three groups with regard to the MARS-5 ($F_{(df=2,43)}=.047, p=.954$) and DMS scale ($F_{(df=2,43)}=.919, p=.407$).

Qualitative Themes

Experiences of Everyday Racism in the Healthcare System. To explore the first research question regarding African American ESRD patients' possible experience with everyday racism in the healthcare system, participants were asked if they were treated fairly in the healthcare system in general and the dialysis center in particular. Several

participants articulated unfair treatment which they attributed to being African American. For example one male participant related,

“The first nephrologist that I had was African American. And he had been a nephrologist for a long time. He tended to take more care with his African American patients. Because that was his culture. The Caucasian nephrologist, I don’t think that he, in fact I know he didn’t give me the same level of care. And it could be due to him seeing me as a race more than a dollar sign.”

When an elderly male participant who has been on dialysis for 30 years told me that he had experienced unfair treatment because of his race, he added, “They try to hide it. You know, because they can’t be obvious about it.”

When I queried further three themes of unfair treatment emerged: 1) concern that invasive procedures would be conducted unnecessarily 2) the fear of being treated without consent 3) different rules in dialysis clinics for Whites and African Americans. The following is a description of each of these themes

Concern regarding invasive procedures. This theme relates to participants’ expressed concern that doctors were more likely to perform invasive procedures on African Americans than Whites, which some connected with the historical abuse of African Americans’ in the medicine. For example, one male participant stated,

“ I have noticed amongst African American men and it's almost like when I go back to look at the roots, most African American men in our clinics have their legs amputated. Most of the White men do not. It's almost like if you have a sore, cut it off. You have a leg, cut it off. You have some issue, cut it off but I've seen that amongst African American men. I don't see that amongst Caucasian men. I don't see that.”

Another participant spoke at length about his constant fear for two years that doctors were going to perform “cut up surgery” on his toes. He explained that his toes looked strange but were fine because they had been like this for two years. He asserted that he knew his body but every few months when the nurses examined his toes they would say, “It's bad. That's dark. You got to get that cut off.’ They put that in your head. And these were two Caucasian nurses that told me that. ‘You got to go see doctor. You got to get them toes cut off. They don't look good.’ And they write it on the chart, need to go see the doctor and amputation. My toes ain't been cut off, yet. This is from two years.” He went on to say, “They're quick to cut on African American people because there's a way, you don't care no way.”

A few participants introduced the idea of African Americans being used as “guinea pigs” as a reason for the differential treatment. As a female participant explained,

“But the thing that saved me, I got a Black African surgeon, Dr. B. Those (other) doctors, ‘Oh, Miss. D., we need to take your legs.’ Dr. B. came in there, he said ‘Miss D.,’ he said, ‘don't let them cut your leg off.’ He said, ‘Y'all are guinea pigs.’”

One male participant interjected,

“And with Black males, it goes so far back to so many things that the trust level between Black males and doctors is not there. So many instances where-- there's the Tuskegee experiment. There are so many evil things that have happened.”

At that point another participant with anger in his voice concurred,

“But I do believe we get guinea pigged, we get cut on, we get experimented on, because from what I understand and when I've been doing a little research they don't consider African American people really citizens of the United States. We can send

everyone else back, but we can't send African American's because they ruined our heritage. We can't go back to Africa. We can't go back to where we come from so we're here to stay. But when you do the research, they still don't respect us and you can tell by the treatment that we get. That's just the bottom line.”

Fear of treatment without consent. The second theme that emerged is that participants felt that they were given treatment without their consent. They believed that this usually happened to African Americans and explained that they had to be vigilant to make sure healthcare providers did not do something to them without their knowledge. As one participant stated,

“They always try to tell me, ‘Go to sleep.’” Another participant agreed, “They always tell me, ‘Ain’t you ready to go to sleep?’ I ain’t going to sleep. I’ll go to sleep when I get home.”

A participant in another interview stated,

“Everybody (African Americans) told me when I started. They were like, ‘Don't fall asleep now. You better stay awake and watch,’ and everything. And that's what I try to do. I try to stay awake. They (nurses) say, ‘why don't you lay back and go to sleep and stuff?’ And I'm like, “No, I have to watch you all.”

Several participants recounted waking up while nurses were injecting medication into their IV. One participant explained, “I’m like, Uh uh! I said, I don’t know what this is. I ain’t taking that.” Another participant recounted a time when she did go to sleep. She stated,

“I was asleep, and I woke up, they had gave me some iron. I know what iron is for. But nobody told me my level was low or anything. I told them, Stop, until you let me

see the paperwork with what the level was.”

Another participant angrily remembered a recent episode where she woke up to nurses administering medication she had no idea about.

“And like I asked yesterday, ‘What is this you're putting in me?’ at dialysis. ‘Oh, it's all right’ (said the nurse). Yeah, Mother fucker, crazy. No, it ain't all right.” A male participant agreed stating, “You (healthcare provider) want to continue to do something without communicating. They don't consult with you. They don't give you no time.”

Different rules. A third theme emerged concerning the possible experience of everyday racism in the healthcare system among African American ESRD patients. During our discussions participants divulged that they saw White dialysis patients receive preferential treatment. This treatment was in two forms: 1) some Whites were allowed to have family members sit with them during dialysis 2) some Whites were allowed to dialyze when they wanted. Many participants complained that certain White dialysis patients were allowed to have family members sit with them during the dialysis process but they had never seen this extended to African Americans. One participant explained that her daughter went with her during her first dialysis session. She explained,

“It was new to me. I took my daughter. But they let her sit beside me that day but they said, ‘We don't like people in here, because it's violating other people's rights.’ However she noticed, “I know there was a White lady that, no, it was a man. And his daughter and, it would be like three of them would come with him. But they never put them out.”

During another interview, a participant stated,

“That one lady (White) who had the kids come and visit her all the time.” She continued saying that she never saw African Americans with family members in her clinic. When I asked why, she said she was told that it was not allowed, “but they never put them out.”

Another part of this theme is the complaint that some Whites were allowed to dialyze when they wanted while African Americans were not afforded this privilege. One participant angrily related,

“When it comes to race, I did feel like that at one point. There was this one girl, a White girl. We didn't know when she came because she was always there whenever she felt like, she came. But if I had an issue, where I'm literally - not because I'm not coming or I don't fit - I'm in the hospital or I'm in the ER, and they've decided not to admit me, I get a problem. This girl comes whenever she wants to.”

Others described how their dialysis times were changed to less desirable times to accommodate Whites.

And then they took the White - they said something, like some of the White people that was coming later - they just put them all in front of me. So I'm like, "Oh, man." they took my time and took it from 6:30 and skipped me all the way back to an hour, to 7:30.” Another participant stated, “But I noticed that they, Whites, all get to come early.”

Attributions & Implications of Unfair Treatment. Three themes emerged regarding unfair treatment attributed to race and its effect on medication and medication adherence: 1) Concern that medical providers were not knowledgeable about the medications they were prescribing 2) Concern that the medication was not safe 3)

Information about medication and lab results being withheld or given to participants without further consultation. The results of these themes on their medication adherence were fourfold. First, participants stated that they took less medication than prescribed or did not take their medication at all. Second, participants explained that they stopped taking their prescribed medication and replaced them with alternative remedies such as herbs and vitamins. Third, participants explicated that they choose a day every week where they do not take medications. Some referred to this as a ‘vacation from medication’. The rationale of this choice is that they would receive less of the negative effects of their medication if they took it fewer times each week. Lastly, participants spoke of replacing and minimizing medication intake through self-directed changes in their diets. For example, participants described decreasing their sodium, fat, phosphate, and sugar dietary intake. Thus they felt that they could decrease the amount of medication they took daily without input from medical providers.

Concern about medical providers’ knowledge of medications. The first theme concerning medications that participants articulated was a concern that medical providers were not knowledgeable about the medications they were prescribing and encouraging the participants to take. This concern made some participants wary of taking the medication prescribed. Thus some participants just did not take the medication or took less than was prescribed. As example, one participant tearfully stated,

“If I ask you a question about my health and my medication, and you can't tell me, what you're doing to me? You're killing me because you're killing me mentally or physically.”

Another participant recounted a time when he was prescribed many medications by a nephrologist at his clinic. He had severe complications because some of his drugs interacted. As a result, he had to be hospitalized and sometimes did not take medication as prescribed because he was fearful of more problems. He asserted, “If you give me a medication, you're a doctor, I want this doctor to know what you're giving me.”

Concern that the medications are not safe. Another theme that emerged was the concern that the medications prescribed were not safe. There was a sense amongst some participants that the medical community did not have their best interests in mind and this extended to the medication that they were prescribed. As one participant stated,

“I mean, it's almost like we are the guinea pigs. We are being used as, ‘Well, let's try this (medication),’ without consulting, without explaining, without being detailed.”

Another lamented,

“Because I've found that the nurse comes up and puts stuff in my IV all the time, that makes me sick.”

Others felt that the medicine they are prescribed might work well with White people but were detrimental to African Americans. One participant asserted,

“But you can't just take a generic medicine across the board. This is affecting the African American people. This is what's better for you (White person), this is what she used, that's what she used, I'm going to prescribe this to you and your body rejects it. Yes, I think they're medicines that are generic and we're guinea pigs. Yeah, I do believe. ‘Well, this is what everybody else takes.’ But everybody's body is not the same.”

Differential treatment regarding information. The last theme is that information about medication and lab results were withheld or given to participants without further consultation. In contrast, White patients received in-depth consultation. As one participant stated,

“Because the dietitian where I’m at, she will go in really detailed depth detail with a White person and she won’t go in detail too much with me.”

Another explained,

“But sometimes when you (medical provider) go to one of the White patients you’ll tell them why. You’ll sit and explain it to them, but some of us you’re just passing us by giving us a sheet saying, okay da dada and that’s it.”

Another echoed,

“And they don’t tell you everything. Then another PA [physician assistant] come through, ‘Well, you know you have blood pressure issues?’ Or ‘Your cholesterol was high this time,’ or ‘You’re taking this,’ or ‘I’m going to put you on this.’ Well, the doctor just left here and he didn’t tell me nothing. ‘Don’t you know your cholesterol is elevated?’ ‘No.’ They don’t go through and fine-tune your thing, they rush through it.”

Yet another stated,

“No. It’s almost like they’re not there, they just check in with you and move on.”

The overall sentiment from the participants who described unfair treatment attributed to race and its effect on medication adherence was that their opinion and concerns were disregarded. As explained by a participant,

“Well, if you don’t consent to taking this medicine, they done gave you anything. And

then, if I got a White lady sitting beside me, you could hear them explaining to her what this medicine is.”

Thus if the participants had concerns about their medication, they were given another medication without proper consultation. Then they witnessed White patients given much consultation just after the physician left them. Therefore, the participants felt neglected and ignored by their medical providers which in turn made them wary of the medication prescribed. It also made them wary of the source of the medication information. Hence some participants explained that they did not trust their medical providers’ directives and turned to the White patients in their dialysis centers instead for medication information. Then they took this information to their medical providers and advocated for the medication the White patients were receiving. One participant stated,

“I’ve got more good information from P. (patient) than any doctor, any clinic, he gave me more good information than anybody.”

When asked why they thought that medical providers were not giving them the best medication information, participants cited three reasons. The participants explained when asked that the reason for the differential treatment was usually based on their race. First, they stated that they felt the medical establishment viewed them as ignorant. Even a participant who had a doctorate in physics explained that she was viewed as ‘stupid’ until she began using medical terminology and verbalizing an understanding of her kidney disease. Second, several participants explained that medical providers seemed to have the perception that they were ‘better’ than them. Patients felt that they were “less than” the providers and that this was exacerbated by race.

Lastly, some African American male participants explicated that medical providers appeared afraid of them because of their race. One participant tearfully recounted an incident where the White nephrologist called the local police to detain him. He explained that he showed up the day he was scheduled for dialysis and the receptionist said he had the date wrong. He protested and the nephrologist disagreed with him. He refused to leave because he was due for dialysis, so the nephrologist called the police. The participant explained that he felt so humiliated and discounted but had to continue going to the clinic because he has no ability to travel to another clinic.

Other Contributors to Medication Adherence. For those participants who did not articulate racism as a barrier to their medication adherence, the researcher explored what barriers the participants experienced. Participants gave several reasons why they had difficulty adhering to their medication regimen. Some explained that the timing of taking medications just did not work for them.

“The way the doctors wanted me to do it, I couldn’t adhere to that schedule. It was just too difficult because you know, I had two pills that they wanted me to take three times a day. And then I had a couple pills they wanted me to take four times a day.”

Others explained that since they often have to take medicine with meals that going out to eat sometimes leads to missed doses.

“But that’s the hardest thing for me is when I go out to eat, and I like to eat out. But like today I went for lunch, and I couldn’t find my pills, and I was like, ‘Ugh! OK.’”

Another participant echoed this.

“So you know, we make sure at dinner we’ll take them, but I don’t, but I knew I had put them in my bag, but I don’t know what happened. Something happened.”

Others complained that the side effects of the medication resulted in them missing doses. “So it just goes from one side effect to another, and the side effects are worse than what you’re trying to fight.” While some participants explained that they did not think the medicine was helping them in anyway because they didn’t “feel the effects of it.” Lastly, participants related that it was simply difficult to remember to take their medication because they were busy. “I might mess around. I might be here. I might be there. I might mess around and go out of town. So I might mess around and miss a treatment, miss taking my medicine.” Being busy with life was often combined with the sentiment that there were so many pills to take. “And it was just, I had to set my alarm on my phone in order to remember when to take all these medications.”

Quantitative Results

The purpose of the quantitative study was to ascertain if there was a statistically significant relationship between everyday racism in the healthcare system (DMS) and medication adherence (MARS-5). Since there is not an overall significant difference among the three groups with regard to the MARS-5 and DMS scale, the groups were combined ($N=46$) for analysis using the Pearson’s correlation. The results of the Pearson’s correlation show a significant negative relationship ($r = -.477, p < .01$) between medication adherence and everyday racism in the healthcare system, so the null hypothesis was rejected. In other words, participants who have lower medication adherence report experiencing more everyday racism in the healthcare system. Furthermore, the independent variable, everyday racism in the healthcare system explains 23% $(-.477)^2$ of the variance in medication adherence. According to Cohen (1988), a correlation coefficient between .30 and .49 is considered moderate correlation.

Follow-Up Question for each item of the DMS Scale. As part of the DMS scale, there is a the follow-up question that is included in the original Everyday Racism Scale from which the DMS scale is based (Williams, Yu, Jackson & Andersen, 1997).. The DMS scale applies the construct, everyday racism, specifically to the health care system. The original Everyday Racism Scale included a follow-up question after each survey item. For example, if participants denote that they experienced everyday racism, they are prompted with: “What do you think was the main reason for this experience?” Table 4.2 shows frequencies for participant responses to each survey question.

Table 4.2: Follow-Up Questions for Each Item of DMS Scale (n=46)

Question	Main Reason n(%)						
	Race	Age	Other Aspect of Physical Appearance	Gender	National Origin/Ancestry	Education/Income Level	Weight
Treated with less courtesy	8(17.4)	3(6.5)	4(8.7)	3(6.5)	—	2(4.3)	1(2.2)
Treated with less respect	7(15.2)	3(6.5)	3(6.5)	2(4.3)	—	1(2.2)	2(4.3)
Receive poorer service	5(10.9)	2(4.3)	2(4.3)	2(4.3)	1(2.2)	1(2.2)	—
8 Doctor/nurse acts as if he or she thinks you are not smart	9(19.6)	2(4.3)	3(6.5)	2(4.3)	—	2(4.3)	1(2.2)
Doctor/nurse acts as if he or she is afraid of you	5(10.9)	—	1(2.2)	1(2.2)	1(2.2)	1(2.2)	—
Doctor/nurse acts as if he or she is better than you	4(8.7)	2(4.3)	2(4.3)	2(4.3)	—	4(8.7)	—
Feel like a doctor/nurse is not listening to what you were saying	4(8.7)	1(2.2)	2(4.3)	3(6.5)	—	5(10.9)	1(2.2)

CHAPTER 5

DISCUSSION

The intent of this study was to examine the possible relationship between everyday racism in the healthcare system and medication adherence among African American ESRD patients attending two patient-centered conferences. This was investigated by exploring the perceptions and experiences of participants' treatment within the healthcare system through individual and group in-depth interviews. In addition, participants completed surveys regarding medication adherence and everyday racism in the healthcare system. The following is a discussion of findings. Included are a summary of the study and convergence of mixed methods, strengths and limitations of the study, as well as, implications of study for social work through a CRT lens, and recommendations for future research are addressed.

Summary of Study & Convergence of Mixed Methods

A mixed methods research study is beneficial when there is scant knowledge in the extant literature about a phenomenon such as the possible effect of everyday racism within the healthcare system on medication adherence in the ESRD African American population. A mixed methods study also provides a more comprehensive account of the studied phenomenon leading to an increased credibility of findings (Creswell & Clark, 2011). Furthermore, a mixed methods study allows the researcher the ability to ascertain if the two forms of research converge or diverge (Creswell & Clark, 2011).

This research study has led to a more comprehensive understanding of the relationship between everyday racism in the healthcare system and medication adherence within the sample of African American ESRD studied. Four research questions were explored for the qualitative portion of the study:

- 1) Do African American ESRD patients experience everyday racism in the healthcare system?
- 2) If so, does everyday racism influence their medication adherence?
- 3) In what way does everyday racism influence their medication adherence?
- 4) If everyday racism is not a barrier to medication adherence, what is?

In response to the first question, three themes of unfair treatment emerged: 1) concern that invasive procedures would be conducted unnecessarily 2) the fear of being treated without consent 3) different rules in dialysis clinics for Whites and African Americans.

In response to the second and third question, three themes emerged from the in-depth interviews regarding unfair treatment attributed to race and its effect on medication and medication adherence: 1) Concern that medical providers were not knowledgeable about the medications they were prescribing 2) Concern that the medication was not safe 3) Information about medication and lab results being withheld or given to participants without further consultation while White patients received consultation.

When asked, the participants explained that these three themes did influence their medication adherence. Participants stated that they took less medication than prescribed or did not take their medication at all. Participants also stated that they stopped taking their prescribed medication and replaced them with alternative remedies such as herbs and vitamins. Some participants explicated that they choose a day every week where

they do not take medications. Some referred to this as a ‘vacation from medication’. The rationale of this choice is that they would receive less of the negative effects of their medication if they took it fewer times each week. In addition, participants spoke of replacing and minimizing medication intake through self-directed changes in their diets. For example, participants described decreasing their sodium, fat, phosphate, and sugar dietary intake. Thus they felt that they could decrease the amount of medication they took daily without input from medical providers.

Lastly, participants gave several reasons for their medication nonadherence that are not related to everyday racism. Participants explained that the schedule for taking their medications that was delineated by their medical provider was too difficult for them to maintain. Others explained that since they often have to take medicine with meals that going out to eat sometimes leads to missed doses. Participants also complained that the side effects of their medication were so harsh that they missed doses. Some participants insisted that they did not feel any effects from taking their medication, so they did not see the utility in taking them as prescribed. Finally, participants stated that they led really busy lives and it was difficult to remember to take their medication.

Because this is a mixed methods research study, it is important to ascertain if the qualitative and quantitative results converge and support one another or diverge. In this study, the qualitative and quantitative results converge. It was hypothesized that there would be a statistically significant negative relationship between everyday racism in the healthcare system and medication adherence among the African American ESRD patients sampled. Indeed there was a significant negative relationship ($r = -.477, p < .01$) between medication adherence and everyday racism in the healthcare system. According to

Cohen (1988), a correlation coefficient between .30 and .49 is considered moderate correlation. In other words, participants who reported lower medication adherence also reported experiencing more everyday racism in the healthcare system. Furthermore, the independent variable, everyday racism in the healthcare system explains 23% $(-.477)^2$ of the variance in medication adherence.

Additional convergence of the quantitative portion of the study with the qualitative portion of the study is evident in the responses of the follow-up questions within the DMS scale. Race was given as the main reason for discriminatory treatment denoted by participants for five of the seven questions. For the sixth question, A doctor or nurse acts as if he or she is better than you, *Race* and *Education or Income level* were the most frequent reason chosen at 8.7% . The final question, You feel like a doctor or nurse is not listening to what you were saying, was most frequently attributed to *Education or Income level* (10.9%). This was followed by *Race* (8.7%). Thus the quantitative data supports the information gleaned during the in-depth interviews giving further credence to the qualitative findings.

Strengths and Limitations

There are three main strengths of this study. First, this is the first study to explore medication adherence within the ESRD population qualitatively. Second, this is the first study which explores everyday racism's impact in general on African American ESRD patients and specifically in relation to medication adherence within the nephrology literature base. Up until this point, the race of research participants was noted in quantitative studies, but no examination of racism has occurred. Lastly, critical race theory (CRT) has never been used as a theoretical framework for nephrology research. In

fact, CRT has rarely been used as a theoretical lens for public health research. Ford and Airhihenbuwa (2010) implore public health social scientists to consider the theoretical implications of CRT as a conceptual foundation for health research. The authors argue CRT provides a theoretical basis for scholars conducting public health research in the area of race equity. Therefore, this study provides new insights regarding medication adherence in the African American ESRD population using a theoretical perspective relatively recent to public health research.

In addition to the strengths, there are several limitations of this study. The qualitative portion consisted of in-depth interviews using convenience sampling while the quantitative portion is a nonexperimental, cross sectional design with convenience sampling. First, although we can determine an association between the independent and dependent variable, it is difficult to determine the temporal relationship. We cannot be sure that the variation in the dependent variable occurred after the variation in the independent variable. The qualitative portion for those participants who were interviewed did allow for an investigation of time order. In fact, several interviewed participants did relate that racism influenced their medication taking. However, the research design is not rigorous enough to make such assertions overall.

Second, spuriousness may also be a factor given the research design. Therefore, the association between the independent variable and the dependent variable might be the result of some other extraneous variable(s) which were not included in the study. Conducting a more expansive study which also includes other known variables which have been shown to impact medication adherence would provide a stronger argument for

the association between medication adherence and everyday racism in the healthcare system.

Third, this study relied on self-reports of the independent and dependent variables. Thus the participants could have provided socially desirable answers to the survey questions. For example they could have reported that they were more adherent to their medications than they really are. One way to alleviate this concern would be to verify medication adherence with patient records. This necessitates approval from the corporations that own most dialysis clinics. It is very difficult to obtain permission to conduct research in the mostly privately owned dialysis clinics. Another way to address this limitation would be a study involving prolonged engagement with participants. Medication adherence could then be measured over time using a measuring device such as the medication event monitoring system (MEMS). MEMS electronically measures each time a medicine container is opened and closed.

Fourth, generalizability is also problematic in this study. Participants were sampled from two patient-centered conferences. Those who participated in the study may be quite different from the larger population of African American ESRD patients. Conducting the study at a dialysis unit or a group of dialysis units would ameliorate this limitation.

However, it is important to note that even though there are several limitations regarding the study, this is the first study to ever examine the impact of everyday racism on medication adherence within the African American ESRD population. Furthermore, these results both qualitatively and quantitatively suggest that everyday racism does impact the participants in the sample. Thus further study is needed to explore this phenomenon in greater detail. Lastly, this dissertation is an important contribution to the

extant nephrology medication adherence literature base. These findings may lead to innovative interventions and further studies which can result in increased medication adherence within the African American ESRD population.

Implications of Study for Social Work Through A CRT Lens

Medication nonadherence within the African American ESRD population is poorly understood and results in increased mortality, hospitalizations, and decreased quality of life. This mixed methods research study using CRT resulted in a greater understanding of the effect of racism on the ability of African American ESRD patients to manage their medication regimens through qualitative interviews. In addition, the research found a statistically significant negative correlation between medication adherence and everyday racism within the healthcare system. The following is a discussion of the implications of this research for social work and their relation to CRT.

The foundational core of CRT is that research leads to social action to address racism. One type of social action is in the form of intervention. Every dialysis patient has a social worker to help them ameliorate the psychosocial barriers to treatment outcomes, including medication nonadherence. Thus the results of this study can serve as the impetus of nephrology social workers to have discussions with African American ESRD patients about race and racism, including within their dialysis unit. As explicated by CRT, Whites are loath to acknowledge the existence of racism in our society. Therefore such discussion rarely occurs. Social workers who are trained in diversity and cultural humility can be equipped to facilitate and engage in discussions about racism in the healthcare system.

In addition, social workers are ethically bound to promote and work towards a core value of the social work profession, social justice. According to the National Association of Social Workers (NASW, 2008), social justice entails “access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people” (p. 3). Furthermore, social workers are ethically bound to challenge social injustice in any form including racial oppression (NASW, 2008). This research has provided evidence that participants experience racism in the healthcare system. Once an injustice is acknowledged, efforts can be made to confront and eradicate the injustice. Social workers can do this by beginning the conversation in their local dialysis clinics.

In the post-civil rights era of “color blind racism,” talk of race or racism may be avoided by Whites in public (Bonilla-Silva, 2002). Therefore honest conversations with dialysis staff and healthcare providers facilitated by social workers about racism may also lead to positive change within dialysis clinics. This could result in changes in the interactions among staff and African American dialysis patients in general and specifically in regards to medication adherence. Such conversations could also lead to anti-racist, culturally relevant interventions with staff and healthcare providers that could be disseminated to other dialysis patients and centers.

Recommendations for Future Research

Given this study, it appears that everyday racism within the healthcare system has an impact on medication adherence for the participants sampled and further research is warranted. First, a quantitative study in which the DMS and MARS-5 are administered to a larger sample would be beneficial. A larger quantitative study would be especially

helpful with the implementation of a more rigorous design such as a randomized control design. Such a design would enable generalization of results to the broader population. To achieve such a design would necessitate sampling from several dialysis clinics or a large hospital affiliated dialysis unit.

Second, a comparison study involving patients from the Northern US and Southern US would be interesting to conduct. It is possible that everyday racism is experienced differently in the Northern US and impacts medication adherence differently or not at all. Third, a more extensive quantitative study could be conducted. A study which includes all of the variables explicated in the literature which affect medication adherence such as health beliefs, depression, and social support. Collecting data on these variables as well as everyday racism in the healthcare system and statistically determining if they are predictors of medication nonadherence using multiple regression would be a helpful contribution to the existing knowledge base. Lastly, a longitudinal study which follows participants over time to ascertain the impact of everyday racism within the healthcare system on their medication taking could provide interesting information. It is possible that everyday racism affects one differently given one's position in their dialysis trajectory. For example, maybe everyday racism has a cumulative effect and those who are exposed to it longer in the dialysis center (more years on dialysis) are less adherent than those who have been exposed to it less (fewer years on dialysis).

Conclusion

In conclusion, this dissertation explores the relationship between medication adherence and everyday racism among a sample of African American ESRD patients. Prior research suggests that African Americans have poorer rates of medication

adherence when compared to Whites. However, the reasons for this racial inequity are not understood. This is particularly troubling since ESRD patients who do not adhere to their medication regimes suffer decreased quality of life, increased morbidity, and death.

Several participants did indeed explain during in-depth interviews that they experienced everyday racism within the healthcare system. Furthermore, this experienced everyday racism did negatively impact their medication adherence. The results of the quantitative analysis support the qualitative accounts. There was a statistically significant negative correlation between everyday racism in the healthcare system and medication adherence. Additionally, race was denoted as the main reason for discrimination experienced in the healthcare setting in six of the seven DMS scale follow-up questions. Thus everyday racism within the healthcare system and its impact on medication adherence within the African American ESRD population deserves further study.

To date, this is the only study that has been conducted with African American ESRD patients to understand the medication adherence racial inequity. This study and studies concerning racial health inequities have particular salience for the social work profession. Social workers are ethically bound to combat social injustice. Racism in any form is a social injustice. Therefore the further examination of injustice reported by participants in this study is a social work imperative. Only through such examination can change occur. Thus this study is a first step in understanding how racism may impact the medication taking of African American ESRD patients. It is clear that everyday racism did play a role in the medication adherence of the participants in this study. Hence, further inquiry is warranted to understand the phenomenon more fully so interventions can be designed

and implemented to address the social injustice.

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APPENDIX A

MEDICATION ADHERENCE REPORTING SCALE

1. I forget to take my medication
 Always Often Sometimes Rarely Never
2. I change the dosage of my medication
 Always Often Sometimes Rarely Never
3. I stop taking my medication for a while
 Always Often Sometimes Rarely Never
4. I decide to skip one of my medication dosages
 Always Often Sometimes Rarely Never
5. I use my medication less than is prescribed
 Always Often Sometimes Rarely Never

The MARS-5 sum score was calculated by summing scores from each individual question (range = 5-25). Higher scores indicate higher self-reported adherence.

APPENDIX B

DISCRIMINATION IN MEDICAL SETTINGS SCALE

1. You are treated with less courtesy than other people.
 Always Most of the Time Sometimes Rarely Never
2. You are treated with less respect than other people.
 Always Most of the Time Sometimes Rarely Never
3. You receive poorer service than others.
 Always Most of the Time Sometimes Rarely Never
4. A doctor or nurse acts as if he or she thinks you are not smart.
 Always Most of the Time Sometimes Rarely Never
5. A doctor or nurse acts as if he or she is afraid of you.
 Always Most of the Time Sometimes Rarely Never
6. A doctor or nurse acts as if he or she is better than you.
 Always Most of the Time Sometimes Rarely Never
7. You feel like a doctor or nurse is not listening to what you were saying.
 Always Most of the Time Sometimes Rarely Never

The DMS sum score is calculated by summing scores from each individual question (range = 7-35). Higher scores indicate higher self-reported discrimination in the medical setting.

APPENDIX C

SURVEY

Thank you for taking part in this survey. Please answer the following

1. What is your Gender? (Circle one)

Female Male

2. Age: _____years

3. Please specify your ethnicity. (Circle one)

Black or African American

White

Hispanic or Latino

Native American or American Indian

Asian / Pacific Islander

Other

4. What is the highest level of education you've completed? (Circle one)

Some high school [9-11 years] or less

Graduated high school/GED

Graduated college (Bachelor's Degree)

Completed Graduate Studies (Master's or Doctorate Degree)

5. What insurance do you use to pay for your healthcare? *Check all that apply, indicate if it is primary, secondary*

	Primary?	Secondary?
Public Aid/Medicaid		
State Renal Program		
Medicare		
Private insurance		
None		

6. Number of pills taken daily for dialysis: _____pills

Please answer the following questions based on your personal experience. There are no right or wrong answers. Please circle your response.

1. I forget to take my medication

Always Often Sometimes Rarely Never

2. I take a different dosage of my medication than my doctor prescribes

Always Often Sometimes Rarely Never

3. I stop taking my medication for a while

Always Often Sometimes Rarely Never

4. I decide to skip one of my medication dosages

Always Often Sometimes Rarely Never

5. I use my medication less than is prescribed

Always Often Sometimes Rarely Never

Please answer the following questions based on your personal experience when receiving treatment for your kidney disease. Please think about your interactions at your dialysis clinic, during other doctor's visits and hospital visits outside of your dialysis clinic. There are no right or wrong answers. Please circle your response.

When receiving treatment for your kidney disease:

1. You are treated with less courtesy than other people.

Always Most of the Time Sometimes Rarely Never

If you answered **Always, Most of the Time, Sometimes, or Rarely**, what do you think was the main reason for this experience? **Please circle your response:**

- a. Your Ancestry or National Origins
- b. Your Gender
- c. Your Race
- d. Your Age
- e. Your Religion
- f. Your Height
- g. Your Weight
- h. Some other Aspect of Your Physical Appearance
- i. Your Sexual Orientation
- j. Your Education or Income Level

2. You are treated with less respect than other people.
Always Most of the Time Sometimes Rarely Never

If you answered **Always, Most of the Time, Sometimes, or Rarely**, what do you think was the main reason for this experience? **Please circle your response:**

- a. Your Ancestry or National Origins
- b. Your Gender
- c. Your Race
- d. Your Age
- e. Your Religion
- f. Your Height
- g. Your Weight
- h. Some other Aspect of Your Physical Appearance
- i. Your Sexual Orientation
- j. Your Education or Income Level

3. You receive poorer service than others.
Always Most of the Time Sometimes Rarely Never

If you answered **Always, Most of the Time, Sometimes, or Rarely** what do you think was the main reason for this experience? **Please circle your response:**

- a. Your Ancestry or National Origins
- b. Your Gender
- c. Your Race
- d. Your Age
- e. Your Religion
- f. Your Height
- g. Your Weight
- h. Some other Aspect of Your Physical Appearance
- i. Your Sexual Orientation
- j. Your Education or Income Level

4. A doctor or nurse acts as if he or she thinks you are not smart.
Always Most of the Time Sometimes Rarely Never

If you answered **Always, Most of the Time, Sometimes, or Rarely**, what do you think was the main reason for this experience? **Please circle your response:**

- a. Your Ancestry or National Origins
- b. Your Gender
- c. Your Race
- d. Your Age
- e. Your Religion
- f. Your Height
- g. Your Weight
- h. Some other Aspect of Your Physical Appearance
- i. Your Sexual Orientation
- j. Your Education or Income Level

5. A doctor or nurse acts as if he or she is afraid of you.
Always Most of the Time Sometimes Rarely Never

If you answered **Always, Most of the Time, Sometimes, or Rarely**, what do you think was the main reason for this experience? **Please circle your response:**

- a. Your Ancestry or National Origins
- b. Your Gender
- c. Your Race
- d. Your Age
- e. Your Religion
- f. Your Height
- g. Your Weight
- h. Some other Aspect of Your Physical Appearance
- i. Your Sexual Orientation
- j. Your Education or Income Level

6. A doctor or nurse acts as if he or she is better than you.
Always Most of the Time Sometimes Rarely Never

If you answered **Always, Most of the Time, Sometimes, or Rarely**, what do you think was the main reason for this experience? **Please circle your response:**

- a. Your Ancestry or National Origins
- b. Your Gender
- c. Your Race
- d. Your Age
- e. Your Religion
- f. Your Height
- g. Your Weight
- h. Some other Aspect of Your Physical Appearance
- i. Your Sexual Orientation
- j. Your Education or Income Level

7. You feel like a doctor or nurse is not listening to what you were saying.
Always Most of the Time Sometimes Rarely Never

If you answered **Always, Most of the Time, Sometimes, or Rarely**, what do you think was the main reason for this experience? **Please circle your response:**

- a. Your Ancestry or National Origins
- b. Your Gender
- c. Your Race
- d. Your Age
- e. Your Religion
- f. Your Height
- g. Your Weight
- h. Some other Aspect of Your Physical Appearance
- i. Your Sexual Orientation
- j. Your Education or Income Level

APPENDIX D

INFORMED CONSENT LETTER

AFRICAN AMERICAN END-STAGE RENAL DISEASE PATIENTS AND MEDICATION

ADHERENCE: WHAT ARE THE EFFECTS OF EVERYDAY RACISM

Thank you for agreeing to participate in this study. The purpose of this study is to ascertain the meaning that African American ESRD patients may ascribe to the effects of everyday racism within the healthcare system on their ability to adhere to their medication regimens. You are being asked to participate in this study because you are an African American End-Stage Renal Disease patient. This study is being conducted by Tamara Savage, a doctoral candidate, and Dr. Teri Browne from the College of Social Work at the University of South Carolina

There are two parts of the study. The first part is an interview will last for approximately 1 hour. If you consent, the interview will be tape recorded. The second part is a 10 minute survey. Your participation is voluntary and you can end your participation at any time. Furthermore, you do not have to answer any questions that you do not want to. There is no cost to you to take part in this study. In addition, your responses are confidential, and any information that you share will be kept confidential by the researchers. No names will be mentioned in the final report. You may choose not to take part or quit the interview at any time at no penalty to you. You will receive \$25 as a thank you for helping us understand the possible role of everyday racism within the healthcare system in the medication adherence of African American ESRD patients.

If you have questions now or during the session, please ask. If you have any questions after the interview, please call Tamara Savage at (910)-620-3002. Also, if you have questions later, you can also contact:

Dr. Teri Browne
College of Social Work
University of South Carolina
Columbia, SC 29208
(803) 777-6258, browne@sc.edu

You can keep this consent letter for your records and future reference. Thank you in advance for your help with my study!

APPENDIX E

INFORMED CONSENT LETTER-SURVEY ONLY

AFRICAN AMERICAN END-STAGE RENAL DISEASE PATIENTS AND MEDICATION ADHERENCE: WHAT ARE THE EFFECTS OF EVERYDAY RACISM

Thank you for agreeing to participate in this study. The purpose of this study is to ascertain the meaning that African American ESRD patients ascribe to the effects of everyday racism within the healthcare system on their ability to adhere to their medication regimens. You are being asked to participate in this study because you are an African American End-Stage Renal Disease patient. This study is being conducted by Tamara Savage, a doctoral candidate, and Dr. Teri Browne from the College of Social Work at the University of South Carolina

The study consists of a 5-10 minute written survey. Your participation is voluntary and you can end your participation at any time. Furthermore, you do not have to answer any questions that you do not want to. There is no cost to you to take part in this study. In addition, your responses are anonymous, and any information that you share will be kept confidential by the researchers. No names will be collected and there will be no way to match any individual with given responses.

If you have questions now or while filling out the survey, please ask. If you have any questions after completing the survey, please call Tamara Savage at (910)-620-3002.

Also, if you have questions later, you can also contact:

Dr. Teri Browne
College of Social Work

University of South Carolina
Columbia, SC 29208
(803) 777-6258, browne@sc.edu

You can keep this consent letter for your records and future reference. Thank you in advance for your help with my study!

APPENDIX F

INTERVIEW GUIDE

INTRODUCTION (10 minutes)

1. Thank you for agreeing to be interviewed. I would like to talk to you about your experiences with the medical system, including things like the medications prescribed for you, doctor's recommendations, how you are treated by medical staff, and so on..
2. Review consent letter. Ask for questions and obtain signature if participant agrees to participate.
3. Ask if it is alright to audio tape. If so, begin taping. If not, take notes.

QUESTIONS (30 to 50 minutes)

1. Dialysis patients often have to take medications daily. What is it like for you?
[Prompts:]
 - a) What is a typical day like for you when it comes to taking your medications?
 - b) What about other days that are not so typical? What are atypical days like for you when it comes to taking your medications?
2. The medical field often defines medication adherence as taking medication as your doctor prescribes. What are your thoughts about taking your medication like your doctor prescribes? [Prompts:]
 - a) What problems do you experience?
 - b) What gets in the way of taking your medication as prescribed?
 - c) What successes do you experience?
 - d) What helps you take your medication as prescribed?
3. Generally speaking, how are you treated in the healthcare system (by doctors, nurses, pharmacists)? [Prompts:]
 - a) Do you believe you are treated fairly or unfairly?
 - b) If so, what do you think explains this different treatment you receive?
 - c) Can you give me some examples?

4. How are you treated when you express your medical concerns to doctors, nurses, pharmacists? [Prompts:]
 - a) Do you believe you are treated fairly or unfairly?
 - b) If so, what do you think explains this different treatment you receive?
 - c) Can you give me some examples?

5. When you think about your dialysis unit, how are you treated? [Prompts:]
 - How do you feel you are treated by the dialysis staff (doctors, nurses, dietitian, dialysis technicians, social workers)?
 - a) Do you believe you are treated fairly or unfairly?
 - b) If so, what do you think explains this different treatment you receive?
 - c) Can you give me some examples?

 - How are your medical concerns treated by dialysis staff (doctors, nurses, dietitians, dialysis technicians, social workers)? [Prompts:]
 - a) Do you believe you are treated fairly or unfairly?
 - b) If so, what do you think explains this different treatment you receive?
 - c) Can you give me some examples?

6. When you think about those occurrences of racism (if the participants have articulated racism) in the healthcare system including your dialysis unit, how does it or does not affect your medication adherence? Does it play a role in your medication taking? [Prompts:]
 - a) How are you treated when you ask questions about your medications?
 - b) How are you treated if your labs results indicate that you are struggling with medication adherence?
 - c) Do you think you are given the information about your medication and labs that you need?

7. Now that you know what the research is about, is there anything that I should have asked but didn't?

ADMINISTER SCALES (5 to 10 minutes)