

# Structural Racism and the Racial Medication Adherence Inequity Within the End-Stage Renal Disease Population: A New Theoretical Framework

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*Blacks or African Americans are almost four times more likely to develop end-stage kidney disease (ESKD) than Whites (United States Renal Data System (USRDS), 2019). Black or African-American ESKD patients are also less likely to manage their medications successfully compared to White ESKD patients (Browne & Merighi, 2010; Curtin, Svarstad, Keller, 1999). Few studies, however, investigate broad social issues, such as structural racism, as a fundamental cause of the inequity. Furthermore, the interaction of structural racism and societal power dynamics in the form of social and cultural capital and their effect on medication adherence inequity has not been explored. This article examines this interaction and its link to medication adherence inequity in the Black or African-American ESKD population and posits a new theoretical framework.*

## INTRODUCTION

End-stage kidney disease (ESKD) currently affects 746,557 people in the United States (USRDS, 2019). A disproportionate number of ESKD patients are Black or African American (USRDS, 2019). According to the U.S. Renal Data System (2019), the prevalence of ESKD per million of the population for Whites is 1,573. Comparatively, the prevalence of ESKD per million for the Black or African American population is 5,816 (USRDS, 2019). Thus, Blacks or African Americans are over 3.5 times more likely to develop ESKD than Whites (USRDS, 2019).

In addition to being disproportionately affected by ESKD, Black or African-American ESKD patients are less likely to manage their medications successfully compared to White ESKD patients (Browne & Merighi, 2010; Curtin et al., 1999; Saran et al., 2003). However, the reasons for this racial inequity are not understood beyond the identified proximal risk factors. This is particularly troubling since ESKD patients who do not adhere to their medication regimen suffer decreased quality of life, increased morbidity, and death (Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte, & De Geest, 2007; Saran et al., 2003). Hence, medication nonadherence is an important health inequity that is worthy of further investigation.

Given the racial inequity in medication adherence in ESKD patients, the societal response to race is worth consideration. Race is a social construct devised to justify an oppressive social hierarchy that privileges Whites. Therefore, race, "... precisely captures the impact of racism" (Jones, 2000, p. 1212). However, few studies have investigated broader social issues, such as racism, or, more specifically, structural racism,

and their effect on Black or African-American ESKD patients' medication adherence (Kennedy, 2009; Wells & Walker, 2012). Instead, most studies report racial differences and attribute them to micro-level patient risk factors (Andrus & Roth, 2002; Cleary, Matzke, Alexander, & Joy, 1995; Lindberg & Lindberg, 2008). Some studies go further and report the difference in race to the risk factor, SES (socioeconomic status), but do not connect SES in any meaningful way to structural racism or medication adherence, except to add it to the long list of individual risk factors (Bame, Peterson, & Wray, 1993; Curtin et al., 1999; Kalichman, Ramachandran, & Catz, 1999).

A *fundamental cause perspective* allows the expansion of inquiry beyond micro-level risk factors to a broader social condition such as structural racism. To further enrich this analysis, Bourdieu's theory of societal power provides a framework for viewing the impact of structural racism on two forms of capital: social and cultural (Bourdieu, 1986). Sequentially, structural racism affects the societal power (capital) of Black or African-American ESKD patients, and this, in turn, affects risk factors proximally related to medication adherence. Thus, this author contends that structural racism is a fundamental cause of medication nonadherence in Black or African-American ESKD patients. The following is an examination of racial inequity and the role of structural racism as fundamental causes of medication adherence inequity in the Black or African-American ESKD population. Also, structural racism is integrated with Bourdieu's conceptualization of social and cultural capital to produce a new theoretical framework. Lastly, the implications of this new integrated framework and how it clarifies the current understanding of the medication adherence inequity is discussed.

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## THE RACIAL INEQUITY AND RACISM

Racial inequity in medication adherence for ESKD patients is well documented. For example, Curtin and colleagues (1999) found in their study of Black or African-American and White ESKD patients that only race/ethnicity was significantly associated with poor medication adherence. Specifically, 60% of Blacks or African Americans were repeatedly nonadherent compared to 34% of Whites (Curtin et al., 1999). Similarly, Saran and colleagues (2003), in their study of 8,396 ESKD patients, found that Blacks or African Americans were twice as likely as Whites to be nonadherent. Although both authors found that being Black or African American was statistically associated with medication nonadherence, neither measured racism (Curtin et al., 1999; Saran et al., 2003). However, the authors note that racism may be a factor and urge researchers to study the construct (Curtin et al., 1999; Saran et al., 2003).

The relationship between racism and a primary precursor to ESKD, hypertension, is well-established. For instance, Kressin, Orner, Manze, Glickman, & Berlowitz (2010) discovered in their sample of 806 hypertensive Blacks or African Americans that those who reported more discrimination experiences were less adherent to their hypertensive medication regimens. Similarly, Cuffe et al. (2013) found that perceived discrimination was associated with lower medication adherence in their sample of 780 Black or African-American men and women. Lastly, in a study of 134 hypertensive Black or African-American men and women, the author found a negative association between high levels of perceived racism and medication adherence (Daramola, 2008). It is evident that there is a medication adherence inequity associated with perceived discrimination in both the hypertensive population, a primary antecedent to ESKD, and by extension the ESKD population, which is not well understood.

Scholars have attempted to understand this inequity by searching for proximal risk factors. Several risk factors associated with ESKD medication nonadherence are insufficient income, lack of education, lack of access to medications, pill burden, and social support (Browne & Merighi, 2010). However, scant attention has been given to broader social conditions, such as racism, and how they may affect the inequity (Wells & Walker, 2012). More fundamental causation may exist.

Applying the idea of structural racism as a fundamental cause of medication nonadherence in Black or African-American ESKD patients is a novel way of thinking about this inequity. Structural racism is a type of racism which is systemic, in which macro-level systems result in racial inequities. (Powell, 2007; Vaught & Castagno, 2008). Macro-level systems include societal norms, institutions, ideologies, and policies. In a racialized society, these macro systems interact and result in structural racism. The process of structural racism is subtle and does not require any overt racist verbiage or acts

(Bonilla-Silva, 1997; Gee & Ford, 2011; Vaught & Castagno, 2008). Instead, structural racism is embedded in society's social, cultural, and historical fabric (Bonilla-Silva, 1997; Gee & Ford, 2011). Structural racism is normalized and becomes an unquestioned fact, especially by the dominant group. In addition, the complex interaction of many macro systems makes it difficult to detect and to eliminate structural racism (Gee & Ford, 2011). The following is a discussion of structural racism as a fundamental cause of medication nonadherence.

## FUNDAMENTAL CAUSE THEORY

Link and Phelan (1995) argue that broad social conditions explain health outcomes through a group of intervening mechanisms or risk factors. The authors posit that, unless these social conditions are addressed, health outcomes will remain unchanged even though the risk factors are ameliorated. This is because the fundamental cause is still present; therefore, if all the risk factors are suddenly addressed and no longer risk factors, the health outcomes will not disappear. The health outcomes will remain as long as the broader social causes remain (Link & Phelan, 1995). Link and Phelan's (1995) theory is provocative, given that much of social science research has focused on proximal risk factors with the contention that once they are eradicated, then the resultant poor health outcomes will be eliminated. There are three tenets of the fundamental cause perspective: 1) resources such as power and prestige minimize risk and serve as protection from disease; 2) fundamental causes are linked to disease through a series of intervening mechanisms; 3) these intervening mechanisms can change over time, but the relationship between the fundamental cause and the disease stays constant (Link & Phelan, 1995). The following is a discussion of the application of the three tenets to structural racism and medication adherence in the Black or African-American ESKD population.

### ***Tenet 1: Power and Prestige Minimize Risk of Poor Health***

According to the first tenet of the fundamental cause theory, resources minimize the risk of poor health outcomes. Structural racism, however, inherently results in lack of resources for the oppressed group through subtle societal norms, institutional practices, governmental policies, and cultural representations which result in a racial hierarchy that privileges Whiteness and disadvantages Blackness (Gee & Ford, 2011; Powell, 2007; Vaught & Castagno, 2008). Structural racism allows the dominant group to maintain power and control of resources at the expense of the oppressed group (Gee & Ford, 2011; Powell, 2007; Vaught & Castagno, 2008). Thus, a detrimental effect of structural racism in the U.S. is that Blacks or African Americans are denied the health protection that access to resources affords. As a result, Blacks or African Americans are exposed to health risks, which result in adverse health outcomes (American Public Health Association, 2001; Nazroo, 2003; Williams & Collins, 2001).

An example related to structural racism that can be applied directly to medication adherence in Blacks or African-American ESKD patients involves access to pharmacies. The Federal Housing Administration's segregated housing policies inculcated racial housing segregation into our society (Seitles, 1998; Williams & Collins, 2001). The racially restrictive lending policies of the nation's economic institutions additionally supported and perpetuated the practice (Seitles, 1998; Williams & Collins, 2001). Even though refusing to rent or sell a residence based on race was deemed illegal by the enactment of the Civil Rights Act of 1968, residential segregation still exists (Williams & Collins, 2001). Blacks or African Americans are more highly segregated than any other minority group in the U.S. (Logan & Stults, 2011). Also, since the housing crisis in 2007, Blacks or African Americans in poor communities have been disproportionately affected by unfair lending, which does not allow residential mobility (Steil, Albright, Rugh, & Massey, 2018).

As a result of continued residential segregation and unfair lending practices by financial institutions, Blacks or African Americans are often relegated to inferior housing in polluted and impoverished environments with limited access to health-promoting resources such as pharmacies (Gee & Ford, 2011; Williams & Collins, 2001). Amstislavski, Ariel, Sheffield, Maroko, and Weedon (2012) found a dearth of pharmacies, which they called "medication deserts" in poor, often predominately segregated Black or African-American communities. The authors' study involved 408 pharmacies in 168 socio-economically diverse communities and discovered that some poor communities were "medication deserts." The authors also ascertained that pharmacies in poor communities had significantly higher odds of being out of stock of medicine and were more likely to be independent pharmacies. The independent pharmacies offered fewer services and were not open as often or as long per day as chain pharmacies (Amstislavski et al., 2012).

Structural racism in the form of historical governmental policies and banking practices that block Blacks or African Americans from moving from segregated housing has a detrimental effect on Blacks' or African Americans' ability to procure medication. The effects of such macrosystems influenced by racism (structural racism) have led to inadequate pharmacies and "medication deserts." The geographical lack of access to medication is a risk factor for medication non-adherence. This is especially true for patients with ESKD, as they have little physical energy due to their illness to travel great distances to procure medication (Browne, Merighi, Washington, Savage, Shaver, & Holland, 2019).

### ***Tenet 2: Fundamental Causes are Linked to Disease Through a Series of Intervening Mechanisms.***

There is a multitude of intervening mechanisms, generally referred to as "risk factors," that are associated with medication

nonadherence in ESKD patients. Two risk factors often mentioned are lack of education and low income/poverty (Bame et al., 1993; Browne & Merighi, 2010; Caraballo, Lebrón de avilés, Dávila Torres, & Burgos Calderón, 2001; Neri et al., 2011). Both risk factors are related to structural racism.

First, within our racialized society, Blacks or African Americans have often received an inferior education (Williams, 1999). As discussed earlier, historical racial segregation due to governmental policies and restrictive lending policies of banks, as well as current unfair lending, have left many Blacks or African Americans living in social isolation (Gee & Ford, 2011; Seitles 1998; Williams & Collins, 2001). As with residential segregation, Blacks or African Americans were also forced to attend segregated schools. However, *Brown v. Board of Education* stated that separated schools were not equal and laid the legal groundwork for school integration (Williams, 1999). However, residential segregation has continued, and so has school segregation (Williams & Collins, 2001).

Currently, most Blacks or African Americans who attend public schools tend to go to schools within their local school district in which they reside (Williams, 1999). Thus, highly segregated communities have led to highly segregated schools (Williams, 1999). Today, two-thirds of Blacks or African Americans attend schools where more than 50% of the students are Black or African American (Powell, 2007). In addition, such highly segregated schools are 14 times more likely to be high poverty schools (Powell, 2007). Second, Poverty is another result of structural racism, as Blacks or African Americans historically were not able to benefit from income-producing New Deal initiatives because of racist federal policy or buy houses in job-rich suburban areas after WWII (Katznelson, 2005). Furthermore, Southern Blacks or African Americans did not benefit from post-WWII GI Bill opportunities because of rampant discriminatory practices of Southern universities (Turner & Bound, 2003).

This entrenched poverty, consequently, has resulted in impoverished schools. The poverty rate of schools has a profound effect on the educational outcomes of students. Attending a high poverty, highly segregated school results in poor educational attainment (Powell, 2007). For instance, according to the National Assessment of Adult Literacy, 24% of Blacks or African Americans scored below the lowest level of health literacy compared to 9% of Whites (Kutner, Greenburg, Jin, & Paulson, 2006). Health literacy involves the ability to understand medical advice regarding medications, including dosage instructions and the ability to comprehend the instructions on medication bottles (Andrus & Roth, 2002). Therefore, Blacks or African Americans are less likely to have requisite health education, which enables them to adhere to their medication regimen.



Second, in our racialized society, Blacks or African Americans are positioned at the bottom with regard to income. According to the U.S. Census Bureau, the median household income for Blacks or African Americans in 2018 was \$41,361, compared to \$70,642 for Whites (U.S. Census Bureau (USCB), 2019). Similarly, the U.S. Census Bureau reports that, in 2018, the poverty rate for Blacks or African Americans was 20.8% compared to a rate of 8.1% for Whites (U.S. Census Bureau, 2019).

Again, historical, social segregation in the form of policy-enforced residential and educational segregation is the structurally racist antecedent to the current social isolation of Blacks or African Americans (Williams & Collins, 2001). Sequentially, residential segregation has led to educational segregation, which has led to poor educational outcomes.

Consequently, poor educational outcomes result in poor positioning for jobs (Williams, 1999). Therefore, many Blacks or African Americans are relegated to poverty. Those ESKD patients who are impoverished are at a much higher risk for medication nonadherence because they do not have the financial resources to purchase the medication they need. Also, if Blacks or African Americans live in a “medication desert” due to poverty, they do not have the financial resources to travel to pharmacies geographically distant from their residences.

***Tenet 3: Mechanisms Can Change Over Time. However, the Relationship Between the Fundamental Cause and the Health Outcomes Remains Constant.***

The third tenet of the fundamental cause perspective is that the relationship between the fundamental cause and the health outcome remains constant. This is a theoretical tenet that Link and Phelan (1995) posit that will occur over time because social conditions are so entrenched in society. Therefore, the intervening mechanisms between the fundamental cause and the health outcome may change over time given changes in technology and advancements in medicine. However, the fundamental cause will stay connected to the health outcome. Hence, the proposed relationship between structural racism as a fundamental cause of the health outcome, medication nonadherence will remain constant even as new advances are made.

### **BOURDIEU'S THEORY OF CAPITAL**

The proposed integrated theoretical framework combines structural racism with Bourdieu's theory of capital (Bourdieu, 1986). Bourdieu's theory of capital involves the structure of the social world, specifically the effects of social class (Bourdieu, 1986; Weininger, 2005). Social class is a complex construct that involves the stratified socioeconomic hierarchy present in society (Bourdieu, 1986; Weininger, 2005). This stratification privileges some and disadvantages others. Bourdieu postulates that the privilege of those in the upper

class manifests itself in the form of power, and power is embodied in various forms of capital (Bourdieu, 1986). Thus, societal members who are rich in capital inhabit a social class position, which buffers them from lack of resources and enables them to maneuver through society with less effort due to their privileged relationships with people of power and influence.

Two forms of capital explicated by Bourdieu that are salient to this integrated framework are social and cultural capital (Bourdieu, 1986; Weininger, 2005).

First, *social capital* is defined as the powerful and influential social networks to which people have access in society (Bourdieu, 1986; Weininger, 2005). Accordingly, in the U.S., the upper and upper-middle classes have social capital because they have friends and acquaintances with expert knowledge and powerful connections. Conversely, the lower classes have few, if any, powerful relationships in their social networks.

Second, *cultural capital* is defined as the cultural artifacts and ways of interacting with similarly influential members, which are valued by the ruling upper classes (Bourdieu, 1986; Weininger, 2005). Examples include language, dress, art, and education, which are personified by society's influential members. Those endowed with cultural capital have the essential cultural keys to maintain vital relationships within their social network.

### **STRUCTURAL RACISM'S RELATION TO BOURDIEU'S THEORY OF CAPITAL: THE INTEGRATED THEORETICAL FRAMEWORK**

In the framework proposed, structural racism is related to social and cultural capital. By definition, structural racism denies Blacks or African Americans the opportunity to succeed through social institutions and policies such as residential segregation and policies and practices of banks which do not lend fairly (Gee & Ford, 2011; Seitles 1998; Williams & Collins, 2001). Opportunity is quashed through social exclusion and social isolation that results from such institutions and policies. Thus, Blacks or African Americans are excluded and isolated from the opportunity-rich influential social networks (social capital) and cultural markers (cultural capital) of the upper-class, White, dominant group. Consequently, the lack of social and cultural capital perpetuates and reinforces the lower social position of Blacks or African Americans. Since the majority of Blacks or African Americans are not part of upper-class White society, they are not afforded the same benefits that power provides, such as job promotions because of relationships with influential co-workers. As a result, the ability of Blacks or African Americans to succeed socially and economically is truncated.

Structural racism and social and cultural capital combine to influence medication adherence in ESKD patients through the same social and economic pathways described earlier. For example, structural racism leads to power differentials between Blacks or African Americans and Whites of the upper classes. Specifically, these power differentials for Blacks or African Americans manifest themselves as a lack of social and cultural capital. Without influential, powerful social networks, Blacks or African Americans are excluded from resource-rich communities, quality education, and higher incomes (Bourdieu, 1986; Weininger, 2005). Therefore, Blacks or African Americans with low incomes who live in impoverished communities and have ESKD may not have access to pharmacies that stock their many essential medications (Amstislavski et al., 2012). In addition, without a sufficient income, Blacks or African Americans with ESKD may not have the financial resources to purchase all of the necessary medications. Lastly, without quality education, they may not be able to read and understand their prescription directions (Andrus & Roth, 2002; Cleary et al., 1995; Kutner et al., 2006). All of these sequelae to structural racism and the dearth of social and cultural capital lead to medication nonadherence.

### IMPORTANCE OF THE INTEGRATED THEORETICAL FRAMEWORK

The importance of this integrated theoretical framework is that it posits that medication adherence inequity amongst Blacks or African Americans is not the result of biological differences or simply a result of poor personal choices. Instead, the focus of the framework is on upstream variables that are beyond the control of Blacks or African Americans.

First, the framework situates structural racism as a fundamental cause of medication nonadherence. This is a new conceptualization of the causation of the medication adherence inequity in the Black or African-American ESKD population and a deviation from the current literature, which emphasizes proximal risk factors.

Second, the introduction of the theory of social and cultural capital in conjunction with structural racism as a fundamental cause provides a more in-depth explanation of how the medication adherence inequity occurs. The integrated framework allows discernment of the layering of disadvantage that affects the lives of Blacks or African Americans in general and Black or African-American ESKD patients in particular. Specifically, structural racism results in the lack of social and cultural capital, which results in educational and income disadvantages. These disadvantages lead to less access to resources, fewer financial resources to purchase medications, and lessened ability to understand prescription directions.

Third, this framework provides a novel pathway for the explanation of medication nonadherence in Black or African-

American ESKD patients. This is a significant paradigm shift because the conversation changes when medication nonadherence is viewed as the result of structural racism. Medication nonadherence is no longer posited as an individual problem; instead, it is postulated to be a societally induced inequity. Understanding medication adherence inequity as societally induced, as opposed to individually induced, results in different implications for research, policy, and practice.

### IMPLICATIONS OF THE INTEGRATED THEORETICAL FRAMEWORK

There are practice, policy, and research implications for the integrated framework. At the practice level, nephrology social workers can make an impact on racial health inequity. Nephrology social workers could form a community advisory board that could solicit direct input from Black or African-American ESKD patients to make broad community changes from their perspectives. For example, if a “medication desert” exists in a community, social workers can work in partnership with patients to address the medication access issue by appealing to local and chain pharmacies to establish a presence in the “medication desert.” Also, social work provides a unique perspective regarding social justice, as we are ethically mandated to address societal injustices. Social workers could lead in the education of kidney healthcare providers regarding structural racism, as well as antiracist strategies and interventions which could be implemented at the provider/practice level.

Policy change at the agency and societal levels could be the result of this integrated framework. At the provider/practice level, social workers could begin by forming a partnership of professionals and patients. This team could review agency policies through an antiracist lens and make any needed changes. Engaging both patients and professionals in such conversations is empowering and fosters a sense of personal ownership.

At the societal level, policies could be crafted to stop residential segregation by encouraging the revitalization of poor Black or African-American communities, which would increase the tax base. The increased tax base would lead to more money flowing into school systems, which would revitalize poor schools. Incentives such as rent control and tax control could be granted to those already living in the neighborhoods, so they will not be forced out by the changes. As another example, a national living wage could be implemented, which would benefit many impoverished Blacks or African Americans, including those with ESKD.

Regarding research, the subjects of structural racism, social capital, and cultural capital have not been explored in relation to the Black or African-American ESKD population and medication adherence. Since this is a new area for explora-

tion, both qualitative and quantitative research would be fruitful. Qualitative research could give researchers rich information, specifically on how structural racism interacts with a lack of social and cultural capital to affect medication adherence. Quantitative research would allow higher numbers of participants to be surveyed with existing surveys or new surveys generated from the qualitative interviews, which would add to the knowledge base.

## CONCLUSION

In conclusion, structural racism meets the criteria as a fundamental cause of the medication inequity between Black or African-American and White ESKD patients. Furthermore, the interaction of structural racism and social and cultural capital clarifies the relationship as a fundamental cause of medication adherence. Given the postulation of this integrated framework, qualitative and quantitative research should be conducted to further our understanding of the medication inequity. Such research could hopefully lead to policy changes and changes at the practice level, which would ameliorate the inequity.

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