

# End-Stage Renal Disease Patients, Medication Self-management, and Oppression\*

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*Medication self-management is crucial for end-stage renal disease (ESRD) patients. ESRD patients who do not adhere to their medication regimen as prescribed suffer increased hospitalizations morbidity and mortality. Furthermore, ESRD disproportionately affects historically oppressed groups, and there is some evidence that historically oppressed groups exhibit low medication self-management. In an effort to understand this issue, this paper presents a novel conceptual model using critical consciousness as the theoretical foundation. The conceptual model posits that oppression affects factors associated with medication self-management since it is embedded in our culture, society, and institutions, including the healthcare system. This research is salient to nephrology social workers for several reasons. First, the only Medicare mandate for master's level social workers on treatment teams is found in dialysis and kidney transplant centers. Thus, every dialysis patient has a social worker who can help them address all barriers affecting their medication self-management, including oppression. Second, social workers are uniquely trained to discuss topics such as oppression and aid patients as they navigate a possibly oppressive healthcare system. Third, social workers, in collaboration with patients, can make positive changes to oppressive healthcare systems which have a negative impact on patients' health. Lastly, social workers have an ethical obligation to fight social injustice, especially when the outcomes of this social injustice, oppression, can be dire for our patients' health.*

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## INTRODUCTION

There is a large literature base regarding medication self-management and chronic disease with some evidence that historically oppressed groups exhibit low medication self-management (Barton, 2009; Halkitis, Palamar, & Mukherjee, 2008; Shenolikar, Balkrishnan, Camancho, Whitmire, & Anderson, 2006). However, there are few medication self-management studies of patients who have end-stage renal disease (ESRD), and even fewer studies that have measured medication self-management in historically oppressed groups (Karamanidou, Clatworthy, Weinman, & Horne, 2008; Schmid, Hartmann, & Schiffel, 2009). This is troubling, since ESRD disproportionately affects historically oppressed groups: African Americans, Hispanics, Native Americans, and Asians (USRDS, 2018).

It is important to ascertain the specific process of medication self-management in ESRD patients because the treatment for ESRD is uniquely challenging, extending to medication self-management. For example, ESRD patients have the highest pill burden when compared to patients suffering from other chronic diseases (Chiu et al., 2009). Twenty-five percent of ESRD patients take 25 pills or more per day (Chiu et al., 2009; Schmid, Hartmann, & Schiffel, 2009). Those pills must be taken at different times throughout the day and are dependent on meals and fluid intake. It is difficult to establish a daily routine, and this complicates an already complex medication regimen. These medications often have severe side effects, which result in physical discomfort and decreased quality of life (Lindberg & Lindberg, 2008; Neri et al., 2011). Also, ESRD patients must dialyze at least

three times a week for a minimum of three hours *each visit* in an outpatient facility in order to survive (Browne, 2012). Patients are often unable to maintain full-time employment because of the rigorous treatment schedule, and the frequent fatigue from electrolyte shifts that occur during dialysis which results in decreased quality of life (Mayo Clinic Staff, 2010). Furthermore, since dialysis requires permanent vascular access, a surgical fistula or graft is necessary, but usually requires multiple, painful surgeries, which 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). In addition, 66% of ESRD patients with chronic pain are taking prescription medications to control pain, which adds another medication to an already complex regimen (Iacono, 2004). Lastly, ESRD prescriptions are expensive. Compared to the general population, Medicare Part D prescription spending is 4.1 times greater for ESRD patients (USRDS, 2018). Therefore, the treatment for ESRD poses an extraordinary physical and monetary burden. If patients do not adhere to treatment, however, the results include increased morbidity and mortality, especially in the case of missed dialysis (Browne, 2012).

Given the gap in the literature regarding medication self-management amongst historically oppressed ESRD patients, coupled with the unique burdens of ESRD, it is imperative to study the particular factors that influence medication self-management in this population. Therefore, this study provides a conceptual model to understand the factors that influence medication self-management in historically

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oppressed ESRD patients. A discussion of oppression follows and how the concept relates to health outcomes and medication self-management among those with chronic disease in general, and medication self-management among ESRD patients in particular.

### OPPRESSION AND HEALTH OUTCOMES

According to Berg-Weger (2005), oppression is, “the restriction by one group over an individual’s or another group’s ability to gain access to resources or exercise their rights” (p. 1–7). DuBois and Miley (2005) add that oppression involves actions and behaviors that result in a “hierarchical arrangement,” which prevents individuals from gaining access to opportunities (p. 192). Oppression can manifest in several ways, such as racism, sexism, heterosexism, and ethnocentrism, and result in the discrimination and alienation of specific groups (Berg-Weger, 2005; DuBois & Miley, 2005). These manifestations of oppression can be found in the healthcare system, where adverse outcomes and disparities in access, quality of care, and treatment are prevalent among populations who have been oppressed historically based on race or ethnicity, gender, sexual orientation, socioeconomic status (SES), and geography (Darnell & Lawlor, 2012; Sable, Schild, & Hipp, 2012).

There are several examples of poor health outcomes among historically oppressed groups in the literature. Hispanics are twice as likely to die from diabetes (Smedley, Stith, and Nelson, 2005) and HIV-related illnesses (Cunningham, Mosen, & Morales, 2000) than Whites. Native Americans suffer from high rates of death from tuberculosis, influenza (U.S. Commission on Civil Rights, 2004), liver disease, and diabetes (Smedley, Stith, and Nelson, 2005). African Americans die at a higher rate from cancer, heart disease, HIV/AIDS, and cerebrovascular disease than any other racial/ethnic group (Smedley, Stith, and Nelson, 2005). Lastly, cardiovascular disease is the primary cause of death for women, and more women die each year from heart disease than men (American Heart Association Statistics Committee and Stroke Statistics Subcommittee, 2012).

### MEDICATION SELF-MANAGEMENT AND HISTORICALLY OPPRESSED GROUPS

One reason for poor health outcomes can be medication self-management. Medication self-management involves collaboration between patients and their healthcare team in decision-making and problem-solving (Browne & Merighi, 2010; WHO, 2003). Differences in medication self-management have been found amongst historically oppressed groups. For example, Shenolikar, Balkrishnan, Camancho, Whitmire, and Anderson (2006) conducted a study to ascertain levels of medication self-management in a sample of participants who were diabetic. The authors found that the rates for adherence to diabetic medications was 12% lower for African Americans, compared to Whites. 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 address the issue of oppression or attempt to link the concept of historical oppression to lower adherence rates in their samples.

### MEDICATION SELF-MANAGEMENT AND HEMODIALYSIS

Health outcome disparities pertaining to medication self-management also apply to patients receiving dialysis with ESRD. ESRD currently affects 726,331 people in the U.S. (USRDS, 2018). A disproportionate number of ESRD patients are members of historically oppressed racial and ethnic groups (USRDS, 2018). According to the U.S. Renal Data System (2018), the incidence of ESRD per million of the population for Whites is 292.6. Comparatively, the incidence of ESRD per million of the population for African Americans is 858.9; the rate for Hispanics is 451; the rate for Native Americans/Alaska Natives is 352.6; and the rate for Asians is 314.8 (USRDS, 2018). Thus, when compared to Whites, the prevalence of ESRD for historically oppressed populations is higher. African Americans are almost three times more likely to develop ESRD than Whites. Hispanics are approximately 1.5 times more likely to develop ESRD, while Native Americans/Alaska Natives, and Asians are roughly 1.2 times more likely than Whites to develop ESRD (USRDS, 2018).

Little research has been conducted with historically oppressed ESRD patients in regard to medication adherence. Of the few research studies conducted, the research has concluded that 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). For example, Saran and colleagues (2003) conducted a study looking at factors, including age, gender, ethnicity, depression, education, employment, years on dialysis, and smoking, as predictors of medication self-management. The authors found that, “younger age, African-American race, female gender, disabled status, living alone, smoking, depression, and time on ESRD,” were statistically associated with medication nonadherence (Saran et al., 2003, p. 260). Likewise, Curtin, Svarstad, and Keller (1999) found similar results regarding race/ethnicity and ESRD in their study. The authors also looked at several factors including age, gender, race/ethnicity, employment, education, and number of prescribed medications (Curtin, Svarstad, & Keller 1999). They found that only race/ethnicity was significantly associated with poor medication self-management. Specifically, 60% of African Americans were repeatedly nonadherent compared to 34% of Whites (Curtin, Svarstad, & Keller 1999). Again, oppression was not studied as a possible link to unsuccessful medication self-management in historically oppressed participants.

ESRD disproportionately affects historically oppressed groups (USRDS, 2018). However, there has been scant theoretical and conceptual exploration concerning how medication self-management in the ESRD patient population is influenced by historical oppression. As previously delineated,

ESRD is also a disease whose unique challenges may have equally unique determinants of medication self-management. Therefore, the purpose of this paper is to provide a conceptual model regarding the factors that influence medication self-management in historically oppressed ESRD patients.

### THE CONCEPTUAL MODEL

The conceptual model, presented in **Figure 1** below, comprises nine concepts, which influence medication self-management in ESRD patients: *oppression, social class, educational attainment, trust in healthcare system/provider, pill burden, mental health status, health literacy, patient satisfaction, and health beliefs*. An explanation of each concept follows. Since the purpose of the research is to ascertain how oppression may influence medication self-management in historically oppressed ESRD patients, the model and explanation begins with the concept of oppression.

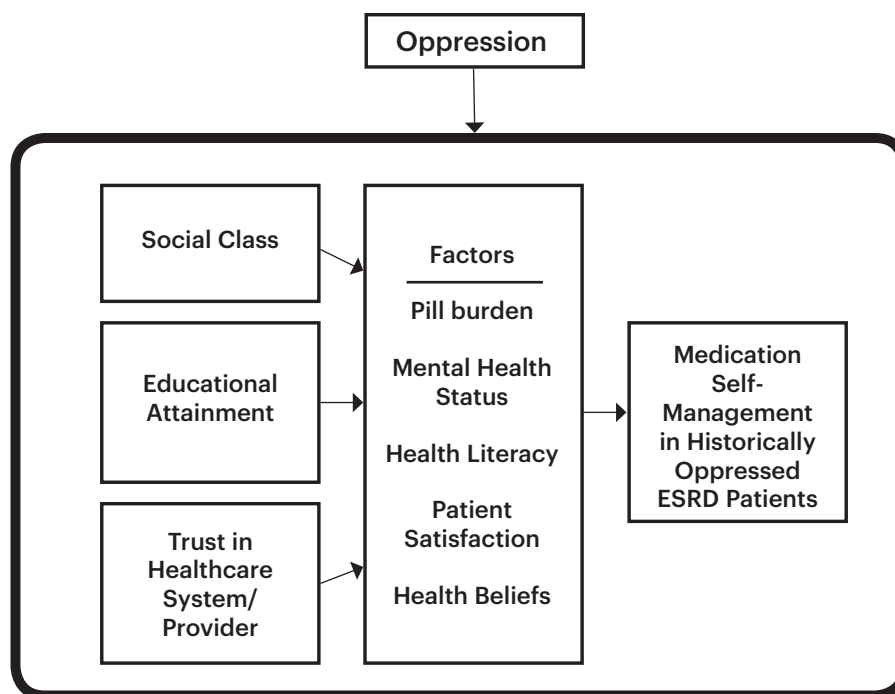
#### Oppression

Oppression is positioned at the top of square which encompasses the other eight concepts depicted in the model because oppression is posited to be an overarching concept that influences the other concepts. Oppression has not been directly linked to medication self-management in ESRD patients. However, Smedley, Stith, and Nelson (2005) note that negative attitudes toward non-White racial groups in the U.S., coupled with current and historical discrimination, provide an important context for the prevalence of disparate health outcomes. Similarly, Williams, Neighbors, and Jackson (2003) argue that the apparent “racialized social

structures” in the U.S. have profoundly negative effects on the health of racial and ethnic groups (p. 206). This conceptual model postulates that the negative effects of oppression also extend to medication self-management. Specifically, oppressive societal structures result in decreased resources and opportunities in historically oppressed ESRD patients.

These decreased resources and opportunities manifest as lower social class (U.S. Census Bureau, 2017), lower educational attainment (National Center for Educational Statistics, 2018; Williams, 1999), lower trust of the medical system (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Freedman, 1998; Kennedy, Mathis, & Woods, 2007; LaVeist, Morgan, Arthur, Plantholt, & Rubinstein, 2002; LaVeist, Nickerson & Bowie, 2000), possible increased pill burden (Chiu et al., 2009), decreased mental health status (Celik, Annaguruz, Yilmaz, & Kara, 2012; DiMatteo, Lepper & Croghan, 2000; Kimmel, Weihs, & Peterson, 1993; Neri et al., 2011), decreased health literacy (U.S. Department of Education/National Center for Educational Statistics, 2003), decreased patient satisfaction (Smedley, Stith, & Nelson, 2005; van Ryn & Burke, 2000), and negative beliefs concerning health. As stated, the conceptual model posits that oppression indirectly shapes historically oppressed ESRD patients’ medication self-management. It is the overarching construct which influences every aspect of the medication self-management process. In the model, social class, educational attainment, and trust in healthcare system/provider are influenced by oppression and directly influence five identified factors of medication self-management (Bame, Petersen, & Wray, 1993; Browne, 2012; Curtin, Svarstad, & Keller, 1999; Kalichman, Ramachandran, & Catz, 1999; Schmid, Hartmann & Schiff, 2009).

**Figure 1.** Conceptual model of factors that influence medication self-management in historically oppressed ESRD Patients



### *Social Class and Educational Attainment*

Social class and educational attainment are indicators of SES, which is considered one of the primary contributors to disparate health outcomes. SES has been widely studied in relation to chronic diseases (Elliott, 2008; Franks, Gold, Fiscella, 2003; Kalichman, Ramachandran, & Catz, 1999; Shavers, 2007; Trinacty et al., 2009; Walker et al., 2006). According to Shavers (2007), income, occupation, and education are standard measures of SES in health research. However, social class is posited as an SES indicator in this conceptual model because it provides more comprehensive information regarding one's position within the socioeconomic realm. Social class is a multidimensional concept comprising wealth, income, occupation, social capital, and social position within a society (Duncan, Daly, McDonough, & Williams, 2002; Karlsen & Nazroo, 2002; Krieger, Williams, & Moss, 1997; Shavers, 2007). Educational attainment is generally defined as the number of years of education completed and/or credentials earned and is also included in the model (Shavers, 2007).

Both social class and educational attainment are influenced by oppression (National Center for Educational Statistics, 2018; U.S. Census Bureau, 2017; Williams, 1999). The constant denial of opportunities and resources has resulted in historically oppressed groups having lower incomes, wealth, and social positions within society as evidenced by poverty statistics (U.S. Census Bureau, 2017). For example, 22.0% of Blacks and 19.43% of Hispanics are impoverished, compared to 8.8% of Whites. In addition, historically oppressed groups also evidence lower educational attainment. According to the National Center for Educational Statistics (2018), 35% of Whites graduated from college in 2016, compared to 21% of Blacks, 15% of American Indians/Alaska Natives, and 15% of Hispanics. Therefore, oppression influences social class and educational attainment, influencing medication self-management in ESRD patients in such a way that patients of lower social class and little formal education are less likely to successfully manage their medications (Bame, Petersen, & Wray, 1993; Browne & Merighi, 2010; Caraballo Nazario, Debron de Aviles, Davila Torres, & Burgos Calderon, 2001; Neri et al., 2011).

### *Trust in Healthcare System/Provider*

A third variable in the conceptual model that is influenced by oppression is trust in healthcare providers and the healthcare system (Armstrong et al, 2008; Armstrong, Ravenell, McMurphy, & Putt, 2007; ). Trust in the healthcare system/provider is defined as a sense that the system/provider is looking out for the best interests of the patient, is honest and competent, and is non-discriminatory and respectful (Armstrong et al., 2008). Trust in the healthcare system/provider plays a significant role in patient adherence to medication and appears to be influenced by oppression (Finnegan et al., 2000; Fiscella, Franks, Gold, & Clancy, 2000; LaVeist, Nickerson, & Bowie, 2000; Paradies, 2006; Van Houtven et al., 2005). It is postulated that historically oppressed patients

may not take their medications because they do not trust the healthcare system related to past abuses committed against historically oppressed patients by the medical system or current negative attitudes in the medical system toward non-White racial groups (Smedley, Stith, & Nelson, 2005; Williams, Neighbors, & Jackson, 2003). Because of the mistrust due to past abuses, historically oppressed populations may have transmitted mistrust to subsequent generations. Thus, ESRD patients from historically oppressed groups may not believe that the medicine given to them by their health provider is safe, so they may refuse to take it as prescribed or not at all. Trust in the healthcare system/provider as it relates to medication self-management has not been studied in the ESRD population. However, the conceptual model postulates that it is an important factor contributing to medication self-management in historically oppressed ESRD patients.

Social class, educational attainment, and trust in the healthcare system/providers, in turn, influence five factors, all of which therefore are affected by oppression. These five factors have been documented in the literature as directly influencing medication self-management and include: *pill burden*, *mental health status*, *health literacy*, *patient satisfaction*, and *health beliefs* (Browne & Merighi, 2010; Chiu et al, 2009; Karamanidou, Clatworthy, Weinman, & Horne, 2008; Schmid, Hartmann, & Schiffl, 2009).

### *Pill Burden*

As mentioned, when compared to patients suffering from other chronic diseases, ESRD patients have the highest pill burden (Chiu et al., 2009). Also, pills are often difficult to swallow due to fluid restrictions, resulting in side effects such as nausea and vomiting, and some are extremely large in size (Chiu et al., 2009; Lindberg & Lindberg, 2008; Schmid, Hartmann, & Schiffl, 2009; Walker et al., 2006). In addition, if laboratory results indicate that medication levels are not within the desired range, ESRD patients who are unsuccessfully managing their medications may be prescribed more pills, further increasing their pill burden (Chiu et al., 2009).

Pill burden coping is indirectly related to oppression, because patients from oppressed groups often do not have the resources to effectively manage the structural barriers associated with obtaining prescribed medication. For example, persons in lower social classes have fewer financial resources in terms of insurance medication reimbursements, available funds for required copays, and travel means for journeys to and from pharmacies (Holley & DeVore, 2006). Educational attainment also influences how ESRD patients cope with pill burden. It is postulated that historically oppressed ESRD patients who did not have the opportunity or resources to attain higher levels of education due to pervasive societal oppression may have more difficulty developing a plan that integrates the complex pill regimen into their daily lives and understanding the consequences of not taking prescribed medications (Bhattacharya, 2012; Shenolikar, Balkrishnan,

Camacho, Whitmire, and Anderson, 2006). Lastly, historically oppressed ESRD patients may not take their medications prescribed by medical providers, who may be seen as representatives of an oppressive and discriminatory medical system, because they may not trust that the pills are helpful or safe (Finnegan et al., 2000; Fiscella, Franks, Gold, & Clancy, 2000; LaVeist, Nickerson, & Bowie, 2000; Paradies, 2006; Van Houtven et al., 2005.)

#### *Mental Health Status*

Second, mental health status difficulties negatively affect medication self-management (Celik, Annaguruz, Yilmaz, & Kara, 2012; DiMatteo, Lepper & Croghan, 2000; Kimmel, Weihs, & Peterson, 1993; Neri et al., 2011). DiMatteo, Lepper, and Croghan, (2000) reported in their meta-analysis of articles concerning medical treatment adherence that depressed patients are three times more likely not to follow treatment regimens than patients who are not depressed. Kimmel, Weihs, and Peterson (1993) determined in their literature review that depression is a prevalent problem in the ESRD population and has negative effects on treatment adherence and overall health outcomes. Similarly, Celik, Annaguruz, Yilmaz, and Kara (2012), in their study of psychopathology in a sample of dialysis patients, found that 62% of the patients exhibited depression.

The conceptual model posits that depression is also connected to oppression since depression is disproportionately prevalent in historically oppressed groups. In a study conducted by the Centers for Disease Control and Prevention (2011), 13% of African Americans, 11% of Hispanics, and 11% of those who identified as multiple races or non-Hispanic persons of other races reported that they were depressed, compared to 8% of Whites. Therefore, members of historically oppressed groups are more likely to experience depression than Whites (CDC, 2011). It can be reasoned that since depression is negatively associated with medication self-management, members of historically oppressed groups who are depressed are at greater risk for unsuccessful medication self-management.

Social class, educational attainment, and trust also directly influence mental health status in ESRD patients. Lower social class and lower educational attainment have been associated with depression (Murali & Oyebode, 2004). Those belonging to lower social classes are faced with many stressors in their everyday lives, such as the omnipresence of oppression, which may contribute to depression. In addition, impoverished ESRD patients may not have resources to obtain aid for depression. Those with lower educational attainment may not be able to understand their condition comprehensively nor access aid as effectively as those with greater educational attainment. Oppression results in a lack of resources which may in turn contribute to depression. Lastly, oppression may influence historically oppressed ESRD patients to mistrust the healthcare system/provider, and they may not seek treatment for their depression.

#### *Health Literacy*

Third, health literacy is necessary in order to follow medication instructions and adhere to medication regimens. Health literacy is defined as the ability to understand basic health information in order to make informed health decisions (Liechty, 2011; U.S. Department of Health and Human Services, 2000). Therefore, health-literate patients have a better understanding of their disease diagnosis and prognosis, as well as medical options regarding their treatment.

Health literacy requires not only the ability to read, but also the ability to navigate the complex system of health information, distill this information, and make decisions regarding one's health (HHS, 2000). In addition, health literacy involves the ability to comprehend important medical-related information, such as informed consent forms, educational brochures, instructions regarding future medical appointments, medication dosage instructions, and insurance payment forms (Browne & Merighi, 2010; Williams et al., 1995). It is estimated that more than one-third of adults are not health literate, which can lead to negative health outcomes (Liechty, 2011).

Inadequate health literacy also has a direct effect on medication self-management. ESRD patients who are unable to read and understand medication insurance forms, medication prescriptions, or pill bottle instructions and labels are unlikely to successfully manage their medication (Browne & Merighi, 2010). Oppression appears to influence health literacy. Members of historically oppressed groups disproportionately experience low health literacy. According to the National Assessment of Adult Literacy, 24% of African Americans, 41% of Hispanics, 13% of Asians, and 25% of Native Americans scored below the lowest level of health literacy compared to 9% of Whites (U.S. Department of Education/National Center for Educational Statistics, 2003). Historically oppressed groups often achieve limited education, experience lower levels of social class, and mistrust the healthcare system/provider (National Center for Educational Statistics, 2018; Smedley, Stith, & Nelson, 2005; Williams, Neighbors, & Jackson, 2003). Those with low levels of education may not have had exposure to medication-related language. If patients do not understand the instructions regarding their medication, many medication mistakes could occur.

Impoverished patients may not have the multiplexity of social connections that are prevalent in higher social classes (Kelly, 1994). Without these social connections, patients from lower social classes are often bereft of resources to call on for help when they do not understand their medication. Mistrust in the healthcare system may also cause patients to discount attempted efforts to increase their health literacy. They may not be taken care of properly because of discriminatory views and actions of medical providers; therefore, they may reject the information provided to them which may lead to unsuccessful medication self-management (van Ryn & Burke, 2000).

### *Patient Satisfaction*

Fourth, patient satisfaction influences medication self-management. Patients who are satisfied with the quality of care they receive from their healthcare team and are satisfied that their concerns and questions are addressed are more adherent to medication regimens (Browne & Merighi, 2010). However, patients from historically oppressed racial/ethnic groups report less satisfaction with healthcare system/providers (Barr, 2004; Carlson, Blustein, Florentino, & Prestianni, 2000; Kutner, Zhang, & Brogan, 2005). There is some evidence that prejudicial stereotypes held by physicians may account for lower levels of patient satisfaction reported by racial/ethnic groups (Smedley, Stith, & Nelson, 2005; van Ryn & Burke, 2000). For example, van Ryn and Burke (2000) found in a study of physicians that race and SES affected physicians' beliefs about their patients. Specifically, physicians expressed that African-American patients were less likely to comply with treatment, were less intelligent and rational, and more likely to abuse drugs than White patients (van Ryn & Burke, 2000).

Patient satisfaction, as with the other factors, is influenced by social class, trust in the healthcare system/provider, and educational attainment. Historically oppressed ESRD patients from lower social classes may experience current oppression in the healthcare system, leading to lower patient satisfaction (van Ryn and Burke, 2000). This is possibly connected with educational attainment in that healthcare providers may view historically oppressed patients with less education as less intelligent and unworthy of the same regard as White patients, which would lower patient satisfaction by members of historically oppressed groups with limited education. In addition, the entire healthcare experience can be confusing and disorienting. Patients with less formal education may find all of the forms and procedures stressful and difficult to comprehend which could lead to less patient satisfaction. Lastly, if patients do not trust the healthcare system/provider, they are less likely to be satisfied with their care (Barr, 2004).

### *Health Beliefs*

Fifth, health beliefs influence medication adherence. Historically oppressed ESRD patients who have low educational attainment may not understand the necessity of the complex medication regimen and the nuances of their disease.

Health beliefs include patients' beliefs about the relationship between perceived disease severity and medication benefits, compared to adverse effects of not taking medication (Karamanidou, Clatworthy, Weinman, & Horne, 2008). A complicating factor related to ESRD is that there are few symptoms that herald the dire outcomes that occur if patients do not take their prescribed medications. Therefore, patients may perceive their ESRD as controlled and decide to skip a medication that causes unpleasant side effects because there are no immediate repercussions (Cummings, Becker, Kirscht, & Levin, 1982). Patients who

do not see benefit of taking medication, and falsely believe their disease is under control, will not continue taking their medication unless presented with worsening symptoms (Wiebe & Christensen, 1997). Unfortunately, once symptoms ensue, irreversible damage to the body may have occurred and result in increased morbidity and mortality (Wiebe & Christensen, 1997).

Health beliefs and medication self-management are indirectly shaped by oppression. Historically oppressed groups may dismiss the dire warnings of a mistrusted healthcare system and erroneously believe their ESRD is controlled when, in actuality, it is not. They may refuse to believe the medical test results because they are a product of a medical system that has committed past medical injustices, and discrimination by a current provider. Social class, educational attainment, and trust of the healthcare system/provider are directly related to healthcare beliefs and mediated by oppression. Historically oppressed patients, who are often from lower social classes, may have higher levels of fatalism (the belief that one has little power to control events in one's life) and lower life span expectations (Wardle & Steptoe, 2003). These patients may be mistrustful of information from the mainstream healthcare system that they must endure medication side effects and manage a complex and large pill burden to prevent dire medical conditions associated with ESRD (Wardle & Steptoe, 2003).

## METHOD

### *Theoretical Model*

The theory of critical consciousness guides this conceptual model. Although the theory of critical consciousness has never been applied to the issue of medication self-management and ESRD dialysis patients, the theory provides a fruitful context for the examination of the factors that influence medication self-management in historically oppressed ESRD patients. Critical consciousness involves gaining a critical awareness of how one's sociocultural reality affects one's life and how one has the capacity to change this reality and effect true change (Champeau & Shaw, 2002). This awareness is generated through education (Champeau & Shaw, 2002). Therefore, from education and awareness of one's personal agency, to effect change actual change may ensue from the belief that transformation is possible (Champeau & Shaw, 2002).

The assumptions of critical consciousness theory are that education will lead to awareness and awareness will lead to transformative action (Freire, 2012). The strength of this theory with regard to the research question is that it provides a theoretical lens through which to acknowledge the unique experiences of members of historically oppressed groups in the U.S. The theory of critical consciousness allows the information ascertained to be understood from the distinctive perspective of the oppressed.

### **Implications of Model Contribution**

The treatment for ESRD is uniquely challenging and complicates medication self-management. Patients suffering from ESRD experience a complex and large pill burden, multiple outpatient dialysis treatments per week which are necessary for immediate survival, extreme fatigue associated with dialysis, multiple surgeries to ensure vascular access for dialysis, chronic pain, and substantial prescription expenses. Furthermore, since historically oppressed groups are disproportionately represented in the ESRD population and there is evidence that these patients experience less success with medication self-management, it is imperative to ascertain how oppression is related to medication self-management.

The influence of oppression on medication self-management has never been studied in the ESRD population. Given the huge multifaceted cost to society and affected groups, a causal possibility such as oppression should be investigated. The conceptual model presented in this paper provides a framework for understanding and examining oppression's possible role in influencing medication self-management in historically oppressed groups with ESRD.

Moreover, the roles of social class and trust in the healthcare system/provider in relation to medication self-management in ESRD patients are posited as important additions to the knowledge base. First, income is generally used as an indicator of SES in ESRD medication self-management literature. However, since social class is a multidimensional concept, comprising wealth, income, occupation, social capital, and social position within a society, the concept provides more complex information about a patient's SES than simple income. Second, ESRD patients' trust in the healthcare system/provider, as the concept relates to medication self-management, has not been studied. Mistrusting one's healthcare system/provider because of past historical medical abuses or current discrimination by the system/provider could lead to less successful medication self-management and deserves further investigation. This is especially important in the ESRD patient population because, if patients do not take their medications as prescribed, they are more likely to suffer frequent hospitalizations and increased morbidity and mortality (Schmid, Hartmann, & Schiff, 2009). Therefore, the addition of these two concepts as they pertain to ESRD medication self-management is an important further contribution to the ESRD knowledge base.

### **Strength/Limitation**

The strength of looking at ESRD medication self-management through the lens of oppression is that it provides a structural view of medication self-management as opposed to an individual view. The extant literature on ESRD medication self-management looks at factors that are controlled by the individual such as health literacy and health beliefs along with SES factors which can also be argued to be influenced by individuals. However, this conceptual model postulates that there is an overarching societal influence, oppression, which cannot be controlled by historically oppressed ESRD patients.

Instead, oppression affects every aspect of their daily lives—including medication self-management. The conceptual model further posits that the SES indicators, social class and educational attainment, are directly influenced by oppression and simply are not controllable individual choices. Instead, the indicators are the result of a lack of resources, as well as opportunities, due to societal oppression.

The limitation of the model is that it may possibly rely too heavily on the overarching concept of oppression and its influence on historically oppressed ESRD patients. It may be that oppression does not affect the medication adherence in the historically oppressed ESRD population to the extent outlined in the conceptual framework. It is possible that the role of oppression is not as pervasive as the model suggests. However, more research is needed to examine this.

### **IMPLICATIONS FOR SOCIAL WORK**

This conceptual model has several implications for social work. Fundamentally, nephrology social work with dialysis populations is a critical practice area for the social work 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 improving treatment outcomes, including issues with low medication self-management. 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.

Furthermore, in the post-civil rights era of "color blind racism," talk of oppression that historically oppressed groups experience may be avoided by Whites in public (Bonilla-Silva, 2002). Therefore, honest conversations about oppression with dialysis staff and healthcare providers, facilitated by social workers, may also lead to positive change within dialysis clinics. Social workers are uniquely trained to lead such conversations about issues difficult for others to navigate. These conversations could result in changes in the interactions among healthcare providers and staff and historically oppressed dialysis patients in general, and specifically, in regard to medication self-management. Such conversations could also lead to anti-oppressive, culturally relevant interventions with staff and healthcare providers that could be disseminated to other dialysis patients and centers.

Lastly, 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). Moreover, social workers are ethically bound to challenge social injustice in any form, including oppression (NASW, 2008). Once an injustice is acknowledged, efforts must be made to confront and eradicate the injustice. Social workers can do this by beginning the conversation in their local dialysis clinics.

## CONCLUSION

The proposed conceptual model provides an innovative way to view medication self-management of historically oppressed ESRD patients using critical consciousness as the theoretical foundation. The model could be translated into an empirical model by using both quantitative and qualitative methodology. Quantitative methods could be used to measure the various concepts in the conceptual model in a sample comprised of historically oppressed ESRD patients. For example, a multitude of psychometric instruments that measure the conceptual model concepts could be provided in survey form for completion by the ESRD patients. Qualitatively the views of historically oppressed ESRD patients regarding the impact of oppression on their social class, educational attainment, and trust in the healthcare system/provider could be gathered using in-depth interviews and would enrich the knowledge base of this uniquely affected group. Also, in-depth interviews could provide the perspective of ESRD patients regarding the impact of oppression on the five factors in the model: pill burden, mental health status, health literacy, patient satisfaction, and health beliefs which, in turn, are postulated by the conceptual model to influence medication self-management.

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