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The Journal of
Nephrology Social Work

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- The Role for Nephrology Social Work in the New Kidney Disease Paradigm
- End-Stage Renal Disease Patients, Medication Self-management, and Oppression
- Measuring Health-Related Outcomes After a Peer-Led Educational Intervention for African Americans with Chronic Kidney Disease

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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RESEARCH

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1) Title page
2) Abstract
3) Text
4) References
5) Appendices (optional)
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7) Tables
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The Role for Nephrology Social Work in the New Kidney Disease Paradigm—Moving Ahead by Remembering How We Got Here

Teri Browne, PhD, MSW, University of South Carolina College of Social Work, Columbia, SC

2019 brings exciting changes to the delivery of kidney disease care in the United States and beyond. We have increasing attention to home dialysis and kidney transplantation as preferred treatment modalities for end-stage renal disease (ESRD), new organizations such as CVS Pharmacy and Cricket expanding leadership in chronic kidney disease (CKD) treatment, innovative treatment options such as wearable and implantable kidneys on the horizon, and a new stream of funding for kidney disease innovation through KidneyX. These changes are happening at the same time that patient-centered research is becoming the standard in outcomes evaluation. Nephrology social workers (NSWs) must act now to position ourselves as leaders in this new kidney disease paradigm; these opportunities present an exciting time for social workers to highlight how our interventions can help patients have the best outcomes as kidney disease care evolves.

In the 1970s, social workers across the country worked hard to make sure a requirement for master's-level social workers (MSW) in all dialysis and kidney transplant settings was included in the 1976 Centers for Medicare and Medicaid Services (CMS) Conditions for Coverage for ESRD settings (Conditions for Coverage, 1976). Again, in the 2000s, social workers advocated successfully for and kept this MSW requirement in the new conditions for kidney transplant and dialysis centers (Conditions for Coverage, 2008; Hospital Conditions of Participation, 2007). This is remarkable in that it is the only disease or treatment type for which Medicare requires an MSW on every interdisciplinary team. In 2019, NSWs must come together once more to ensure that we "have a seat at the table" and demonstrate how social work must be involved in the current changes to kidney disease care.

A March 4, 2019 address by Alex Azar, the Secretary of Health and Human Services, to the National Kidney Foundation highlights key attributes of the new changes to kidney disease care (Azar, 2019). These focus on delaying the progression of kidney disease, creating new options for kidney disease treatment, and increasing innovation of such options. Mr. Azar commented that "today's policies bias providers toward center-based dialysis" and that "dialysis companies are actually disincentivized from helping patients get ready for and find[ing] a transplant." As many barriers to transplant and home dialysis are psychosocial, social workers can play a key role in ameliorating these barriers, leading to changes away from in-center hemodialysis. CMS recently amended the Final Rule for the ESRD Prospective Payment System to increase the number of dialysis patients who get transplants (Medicare Program; End-Stage Renal Disease Prospective Payment System, 2018), and ESRD Networks are promoting efforts to increase the use of home dialysis. All dialysis units must help patients get transplants and improve home dialysis rates—social workers in dialysis centers can lead these efforts with their teams.

As we look forward to these innovations, it is also helpful to step back and remember how we had MSWs mandated in all dialysis and kidney transplant centers. In 2006, the *Journal of Nephrology Social Work* published a review of how the Council of Nephrology Social Workers activated a response to the then-proposed Conditions for Coverage from CMS (Browne, 2006). A major part of that response was the creation of a literature review of the need for nephrology social work and its impact on patient outcomes. Below is this literature review, to remind us all of its importance:

PSYCHOSOCIAL RAMIFICATIONS OF CKD AND ITS TREATMENT REGIMENS

General Information

ESRD is a chronic illness that requires lifestyle changes and accommodations that affect all spheres of living: medical, dietary, social, financial, psychological, and rehabilitative. The lifetime course of the ESRD patient's treatment may include multiple renal transplants and different treatment modalities; vascular and peritoneal access problems; life-threatening infections; amputations; severe bone disease; family dysfunction; changes in functional status and issues of palliative care; and dying. Eighty-nine percent of ESRD patients reported that the disease caused many changes in their lifestyles (Kaitelidou, Maniadakis, Liaropouls, Ziroyanis, Theodorou, & Siskou, 2005). The chronicity of ESRD and the intrusiveness of required treatments inflict renal patients with multiple psychosocial stressors including: cognitive losses, social isolation, bereavement, coping with chronic illness, concern about mortality and morbidity, depression, anxiety, psycho-organic disorders, somatic symptoms, lifestyle disruption attributable to intrusive treatment regimen and its schedule (length, frequency), economic pressures, insurance and prescription issues, employment and rehabilitation barriers, mood changes, body image issues, concerns about pain, numerous losses (income, financial security, health, libido, strength, independence, mobility, schedule flexibility, sleep, appetite, and freedom with diet and fluid), social role disturbance (familial, social and vocational), dependency issues, and diminished qual-

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ity of life (QOL) (DeOreo, 1997; Gudex 1995; Katon & Schulberg, 1997; Kimmel et al., 2000; Rabin, 1983; Rosen, 1999; Vourlekis & Rivera-Mizzoni, 1997).

Unique Psychosocial Needs of Pediatric Patients

Children and adolescents with ESRD may be especially concerned about body image issues related to required vascular accesses (Fielding, Moore, Dewey, Ashley, McKendrick, & Pinkerton 1985). Fifty-nine percent of adolescents with ESRD had poor adherence to their recommended medical regimen (Kurtin, Landgraf, & Abetz, 1994). Infants born with ESRD require frequent hospitalization and medical appointments, have diminished development, may need supplemental nourishment or a feeding tube, and are usually precluded from transplant their first two years (Brady & Lawry, 2000).

Unique Psychosocial Needs of Older Patients

The demographics of the renal patient population have drastically changed, from younger heads of families to an increasingly high percentage of elderly patients with numerous comorbidities and social problems. People 65 years and older, with numerous additional comorbidities and social problems, comprise the fastest-increasing population among ESRD patients (Kutner, 1994b; Mold & Holt, 1993). Older adults with ESRD have more somatic complaints (Chen, Wu, Wang, & Jaw, 2003).

Psychosocial Influence of Comorbid Issues Common with ESRD

ESRD is often secondary to chronic illnesses, such as hypertension and diabetes, which afflict ESRD patients with additional psychosocial issues, and predispose ESRD patients toward frequently accessing health services from many community providers (Merighi & Ehlebracht, 2004c). Low albumin and comorbidities in ESRD patients can independently decrease patient QOL (Frank, Auslander, & Weissgarten, 2003). Coronary artery disease in menopausal women with chronic kidney disease (CKD) is associated with cognitive impairment (Kurella, Yaffe, Shlipak, Wenger, & Chertow, 2005). Diabetic ESRD patients have higher depression scores and affective change scores than those without diabetes (Chen et al., 2003). ESRD patients commonly have pain, which is very intrusive and decreases QOL (Devins et al. 1990). Anemia is common in ESRD patients, which prohibits daily activities, diminishes QOL, decreases energy, and increases fatigue (Schatell & Witten, 2004). Anemia is also associated with lower QOL in adolescents with CKD (Gerson et al. 2004). Restless leg syndrome is common in ESRD patients, which is significantly related to increased anxiety (Takaki et al., 2003).

Psychosocial Issues Related to ESRD:

Sexuality and Fertility Issues

Sexual functioning may be diminished due to ESRD, comorbidities, and medication regimens, and are found to be very important concerns for dialysis patients (Wu et al., 2001). Female patients with ESRD have a low fertility rate due to their abnormal reproductive endocrine function and numerous pregnancy complications. Women on daily home hemodialysis may be more likely to have successful pregnancies (Holley & Reddy, 2003).

Functional Status and Economic Concerns

ESRD patients have a lower functional status than the general population and are likely to need assistance with activities of daily living (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000; Kimmel, 2000). ESRD can also lead to financial loss for patients (Wu et al., 2001).

Quality of Life

ESRD commonly results in diminished patient QOL (Frank et al., 2003; House, 1987; Kimmel, 2000). Social workers can intervene to improve ESRD patient QOL and address psychosocial issues affecting it. Poor QOL with ESRD is significantly linked to patient outcomes: decreased functional status, decreased well-being, increased hospitalizations, increased morbidity, and higher mortality (QOL has been found to be as important a mortality marker as albumin level) (DeOreo, 1997; Kutner, 1994a; Mapes et al., 2004; McClellan, Anson, Birkeli, & Tuttle, 1991; Parkerson, Broadhead, & Tse, 1995). Psychosocial status may be more important than physical status in predicting ESRD patient QOL (Promoting Excellence in End-of-Life Care End Stage Renal Disease Workgroup, 2002).

Issues Affecting Patients' Families and Support Networks

ESRD patients' family members have increased stress and coping issues (Pelletier-Hibbert & Sohi, 2001). ESRD has significant psychosocial ramifications for patients' families and social support networks, and social support can influence ESRD outcomes. Social workers can assist patients' support networks with coping with the stress and losses resulting from ESRD, and assist in helping patients build social support, which can lead to better patient outcomes (Benik, Chowanec, & Devins, 1990; Kimmel, 1990). Patients' spouses and partners cope with role reversal and more responsibilities (Gudex, 1995). Fifty one percent of family members of patients with ESRD reported absences from work related to the patient's illness (Kaitelidou et al., 2005). Parents of pediatric ESRD patients have financial burdens and may be unable to work due to the illness and treatment regimen (Brady & Lawry, 2000; Nicholas, 1999). Parents of pediatric ESRD patients are more likely to have anxiety, depression, and coping problems (Fukunishi & Honda, 1995). Families of ESRD patients are often insufficiently knowledgeable about the illness and its trajectories, medical complications, comorbidities, and treatment options and their impact on lifestyles (MacDonald, 1995). Positive social support, particularly from the patient's family, has been found to be related to better patient outcomes, including improved adherence to the treatment regimen, lower levels of depression, increased activity levels, improved psychological well-being, and improved rates of morbidity and mortality (Burton, Kline, Lindsay, & Heidenheim, 1986; Cohen & Syme, 1985;

Kimmel et al., 2000; McClellan, Stanwyck, & Anson, 1993). It has been shown that dialysis patients' partners experience significant concern and coping issues regarding ESRD and treatment modalities in addition to the patient (Nichols & Springford, 1984; White & Greyner, 1999).

Depression

Fifty-two percent of patients with ESRD have been found to have anxiety (Auslander, Dobrof, & Epstein, 2001; Dobrof et al., 2000). ESRD patients are more likely to be depressed than the general population, with depression incidence as high as 49% (Auslander et al., 2001; Dobrof et al., 2000; Finkelstein & Finkelstein, 1999; Hedayati et al., 2004; Wuerth, et al., 2001).

Depression is a serious problem in ESRD patients. It is significantly related to malnutrition and poor nutritional outcomes (Kimmel, et al., 2000; Koo et al., 2003). Depression has been found to be independently linked to ESRD patient mortality (Hedayati et al., 2004; Kimmel et al., 2000; Paniagua, Amato, Vonesh, Guo, & Mujais, 2005; Shulman, Price, & Spinelli, 1989). And it is linked to greater hospitalizations of ESRD patients (Paniagua et al., 2005). Depressed continuous ambulatory peritoneal dialysis (CAPD) patients have greater incidence of peritonitis (Wuerth et al, 1997).

Depression can diminish ESRD patient QOL (Kalantar-Zadeh, Kopple, Block, & Humphreys, 2001; Mollaoglu, 2004). This is important because poor QOL in ESRD is significantly linked to patient outcomes: decreased functional status; decreased well-being; increased hospitalizations; increased morbidity; and higher mortality (DeOreo, 1997; Kutner, 1994a; Mapes et al., 2004; McClellan, Anson, Birkeli, & Tuttle, 1991; Parkerson et al., 1995).

Rehabilitation

ESRD can have a significant impact on patients' rehabilitation status due to diminished physical status and intrusive treatment schedule issues. Social workers can assist patients in maximizing their rehabilitative status. One study found that only 13% of ESRD patients were able to resume employment after starting dialysis (Dobrof et al., 2000). Kaitelidou, Maniadakis, Liaropouls, Ziroyanis, Theodorou, and Siskou (2005) found in a study of Greek patients that 60% of hemodialysis patients had to change professions or retire due to treatment requirements; only 40% kept their original profession. In that study, 7% of agricultural and 6% of blue collar workers kept the same profession; 55% of white-collar workers were able to keep their jobs; 37% retired before the official retirement age; 64% had absences from work; 39% reported working with ESRD symptoms an average of five days per month during which they were 62% productive. Working patients have been found to be more likely to miss a dialysis treatment (Dobrof et al., 2000), and have been found to be less depressed (Chen et al., 2003). Patients with the best rehabilitation status have a better QOL (Mollaoglu, 2004). Low activity levels in ESRD patients are related to higher mortality (Husebye, Westle, Styrvoky, & Kjellstrand, 1987).

Transplantation-Specific

Psychosocial factors such as finances, depression, relationship changes, and employment lead to transplant immunosuppressant noncompliance (Russell & Ashbaugh, 2004). It has been demonstrated that kidney transplant patients, compared to dialysis patients, have overall improved physical and mental health, lower mortality, greater social functioning and enhanced QOL (Dew, Goycoolea, Switzer, & Allen, 2000; Evans et al., 1985; Gokal, 1993; Simmons, & Abress, 1990). ESRD patients may have significant difficulty transitioning from dialysis to transplantation, due to uncertainty, unpredictability, redesigning goals (Levine, 1999).

Sleeping Problems and Body Image Concerns

ESRD patients often have sleeping problems (Valdez, 1997), and also have body image issues related to vascular and peritoneal access and medication side effects (especially immunosuppressants) (Beer, 1995; Sloan & Rice, 2000).

Poor Self-Management

Poor self-management of the hemodialysis treatment schedule has significant ramifications for patients. Missed treatments and high interdialytic weight gains are associated with increased mortality (Husebye et al., 1987; Saran et al., 2003). In one study, 27–31% of patients missed one dialysis treatment per month; 35–41% signed off of dialysis treatments early; 76–85% had problems with diet; 75% of patients who were coping poorly were likely to miss treatments; and 50% of patients who were coping poorly were nonadherent, resulting in fluid gains (Dobrof et al., 2000). In other studies, 30–60% of dialysis patients did not adhere to recommended diet, medication or fluid recommendations (Bame, Peterson, & Wray, 1993; Christensen & Raichle, 2002; Friend, Hatchett, Schneider, & Wadhwa, 1997).

Suicide

It has been found that ESRD patients may be significantly more likely to commit suicide than persons in the general population (Kurella, Kimmel, Young, & Chertow, 2005).

Ramifications

ESRD treatment outcomes are significantly affected by a patient's psychosocial status (Burrows-Hudson, 1995; Burton et al., 1986). ESRD patients with a poor psychological status are more likely to have poor self-management of the treatment regimen and have greater hospitalizations and higher mortality rates (DeOreo, 1997). ESRD patients who feel they are more in control of their treatment tend to cope better, be better adjusted, and have better QOL. ESRD patients with psychosocial problems and less understanding of the illness and treatment regimen and more likely to have high interdialytic weight gains and missed treatments. Patients’ psychosocial strengths, demographic backgrounds, and issues all affect dialysis outcomes (Auslander et al., 2001). Psychosocial issues (social support levels, adherence to dialysis regimen, coping) related to ESRD are as important as medical issues with regard to increased mortality (Kimmel et al., 1998). ESRD patients' functioning, depression, QOL, and activity levels influence treatment regimen outcomes, including morbidity and mortality (Burton et al., 1986; Gutman, 1983; Port, 1990). Poor laboratory values resulting from poor patient self-management can have significant psychosocial ramifications. For example, a low serum albumin is accepted as a predictor of mortality (Lowrie & Lew, 1990). Many psychosocial issues (such as socioeconomic status, need for dentures, assistance with purchasing groceries, decreased appetite due to depression or anxiety, decreased cognitive ability, management of diet, education, literacy, ethnicity, culture, household composition, insurance and social supports) can negatively contribute to albumin management (Calkins, 1993; Ellstrom-Calder & Banning, 1992; Oldenburg, Macdonald, & Perkins, 1988; Vourlekis & Rivera-Mizzoni, 1997).

EVIDENCE OF EFFICACY OF NEPHROLOGY SOCIAL WORK INTERVENTIONS

CNSW Background Material

ESRD patients require comprehensive psychosocial interventions at various stages throughout the course of their illness due to the multiple losses and psychosocial risks associated with their diagnosis and treatment. Socioeconomic and biopsychosocial barriers exist that negatively affect patient treatment outcomes, resulting in increased morbidity and mortality. The identification of these barriers through a skilled biopsychosocial assessment is critical to maximizing patient outcomes. Providing skilled psychosocial interventions based on this assessment can ameliorate biopsychosocial risk factors for the ESRD patient.

The recognized role of the nephrology social worker (NSW) is to:

- provide initial and continuous patient evaluation and assessment, including patients' social, psychological, financial, cultural, and environmental barriers to coping with ESRD and the treatment regimen
- give patients and their support networks emotional support, encouragement, and supportive counseling
- provide assistance with adjustment to and coping with CKD, comorbidities and treatment regimens
- deliver patient and family education and crisis intervention
- provide information and community referrals
- assist with advance directives and self-determination issues
- facilitate group work, including support groups and patient advocacy groups
- perform case management in coordination with community resources, state agencies, and federal programs
- assist patients with achieving maximum rehabilitative status (including: ongoing assessment of barriers to patient goals of rehabilitation; providing patients with education and encouragement regarding rehabilitation; providing case management with local or state vocational rehabilitation agencies)
- deliver staff in-service education regarding ESRD psychosocial issues
- participate in the facility's quality assurance program
- mediate conflicts between patients, families, and staff
- participate in interdisciplinary care planning and collaboration
- patient advocacy

(Beder, 1999; Beer, 1995; Dobrof, J., Dolinko, A., Lichtiger, E., Uribarri, J., & Epstein, I., 2001; Fortner-Frazier, 1981; Kimmel et al. 1995; McKinley & Callahan, 1998; McKinley, Schrag, & Dobrof, 2000; Merighi & Ehlebracht, 2004c; Nichols & Springford, 1984; Oldenburg et al., 1988; Petrie, 1989; Russo, 2002)

The scope of these tasks is congruent with those traditionally related to medical social work in the realms of prevention, palliation, treatment, and advocacy efforts directed at making healthcare more patient-centered (Dhooper, 1994).

Due to the complex nature of the renal patients' needs and issues, interdisciplinary collaboration of care for renal patients by the team has been found to be necessary for optimal delivery of services. An interdisciplinary approach to CKD patient care (including a master's-level social worker) has been shown to be effective in improving patient outcomes, and is the recommended method of providing CKD patient care (Corsini & Hoffman, 1996, Dunn & Janata, 1987; Gitlin, Lyons, & Kolodner, 1994; Goldstein, Yassa, Dacouris, & McFarlane, 2004; Houle, Cyphert, & Boggs, 1987; Warady, Alexander, Watkins, Kohaut, & Harmon, 1999). The severe psychosocial issues facing ESRD patients necessitate master's-level social work interventions, and research has shown that these interventions are vital to ameliorate the psychosocial barriers to the ESRD treatment regimen.

Nephrology social work has been shown to effectively lower patient depression (Beder, 1999; Estrada & Hunt, 1998). It is recommended that "a good psychosocial support program should be incorporated into the treatment of patients with chronic renal failure to reduce the possibility and severity of depression" (Chen et al., 2003, p. 124). Research indicates that a decrease in depression correlates positively to increased adherence to the ESRD treatment regimen, which has a direct impact on decreasing morbidity and mortality (DeOreo, 1997). Seventy-six percent of depressed dialysis patients indicate that they prefer to seek counseling from the NSW on their treatment team, rather than pursue care from an outside mental health practitioner (Johnstone & LeSage, 1998).

Renal social workers are the “natural source of health policy information for patients, as well as other professionals” (Berkman, Bonander, Rutchik, Silverman, Marcus, & Isaacson-Rubinger, 1990), and they provide information to patients and their families about sources of information that are unknown to the family (Berkman et al., 1990; McKinley & Callahan, 1998). Arthur, Zalemski, Giermek, & Lamb (2000) have shown that nonrenal medical professionals (such as home care or nursing home care providers) are mostly unfamiliar with the ESRD psychosocial issues, such as patient eligibility for Medicare, patient ability to work and travel, patient self-determination issues involving discontinuing treatment, and patients' sexual and reproductive problems. Renal social workers are key in assisting patients in navigating medical services for their multiple needs and advocating for patients with community providers that are not attuned to such special needs.

Nephrology social work interventions have been shown to successfully help: enhance/facilitate social support networks of patients and their families (Brady & Lawry, 2000; Johnstone, 2003; Spira, 1996); patients and their families cope with ESRD and the treatment regimen (Brady & Lawry, 2000; Frank et al., 2003); patients improve dialysis adequacy (Callahan, Moncrief, Wittman, & Maceda, 1998); improve patient outcomes, including anemia status (Spira, 1996; Vourlekis & Rivera-Mizzoni, 1997); and help patients minimize nonadherence to the ESRD treatment regimen (Beder, Mason, Johnstone, Callahan, & LeSage, 2003; Callahan et al., 1998; Johnstone, 2003). Social work education and counseling have been shown to reduce missed patient treatments by 50% (Medical Education Institute, 2004).

Nephrology social work interventions have also been shown to successfully help patients reduce their interdialytic weight gains between dialysis treatments (Auslander & Buchs, 2002; Root, 2005). Clinical social work interventions have been found to:

- improve fluid adherence up to 48% (Johnstone & Halshaw, 2003)
- improve ESRD patients' blood pressure (Beder et al., 2003)
- increase ESRD patients' medication compliance (Beder et al., 2003)
- reduce anxiety in CKD patients (Iacono, 2005; Sikon, 2000)
- improve ESRD patients’ overall QOL (Callahan et al., 1998; Chang, Winsett, Gaber, & Hathaway, 2004; Christensen, Smith, Turner, Holman, Gregory, & Rich, 1992; Frank et al., 2003; Fukunishi, 1990; Johnstone, 2003; MacKinnon & MacRae, 1996; Sloan & Rice, 2000; Spira, 1996)
- improve patient activity level and rehabilitation status (Beder et al., 2003; Callahan et al., 1998; Ericson & Riordan, 1993; Institute on Rehabilitation Issues, 2001; Raiz, 1999)
- decrease patient morbidity and mortality via: increasing dietary adherence, enhancing patient coping and adaptation to ESRD and its treatment regimens, decreasing depression, increasing ESRD patient satisfaction and increasing patients' rehabilitation potential (Cummings, Kirscht, & Levin, 1981; Evans, 1990; Korniewicz & O'Brien, 1994; Lenart, 1998; LeSage, 1998; Parsonnet, 1991)
- reduce patient hospitalizations and emergency room visits (Dobrof et al., 2000)
- assist the patient and family in coping with and adapting to changes brought about by ESRD and its treatment regimens (Berkman et al., 1990; Parsonnet 1991)
- mediate conflicts in dialysis settings (Johnstone, Seamon, Halshaw, Molinair, & Longknife, 1997).

Social work intervention and education increase advance directives completion by 51% (Yusack, 1999). Social work assessment and counseling can encourage patients to get a kidney transplant (Rosen, 2002) and may decrease racial disparity in transplantation (Wolfe, 2003; Wolfe & Toomey, 2004). Psychosocial education and support can help patients stay employed and reduce hospitalizations that may inhibit employment (Grumke & King, 1994; Raiz, 1996; Rasgon et al., 1993). ESRD psychosocial services enhance coping, encourage patient participation in their care, and increase adherence (McKinley & Callahan, 1998).

Nephrology Social Work Interventions are Recommended

Psychosocial assessment can identify suicidal ESRD patients for counseling and other interventions (Kurella, Kimmel, Young, & Chertow, 2005). Witten (1998) recommends that social workers can assist with dialysis adequacy, anemia, and access, thus encouraging rehabilitation, exercise, and employment. NSWs can help enable patients to identify and maximize their resources, and develop effective coping mechanisms (Moores, 1983).

CKD Interdisciplinary Team Care (Including an MSW) is Recommended

Interdisciplinary CKD care is associated with fewer hospitalizations and lower mortality (Goldstein, Yassa, Dacouris, & McFarlane, 2004), and MSW participation can be used to educate nonrenal community care providers on the unique issues related to CKD patient care (Arthur et al., 2000). Social work participation in multidisciplinary patient education has been shown to be important in increasing the number of early dialysis access placements (Lindber et al., 2005). Successful vascular access leads to better dialysis outcomes, lower morbidity and hospitalizations.

Nephrology Social Work Assessment and Intervention Considerations

It is recommended that comprehensive individual psychosocial assessment of ESRD patients be conducted to maximize patient outcomes (Fox & Swazey, 1979). Dialysis patients have been found to have the greatest adjustment issues during the first three months of treatment (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000, 2001).

Social Workers Have Been Shown to Be an Important Part of the Transplant Team

Living donor kidney transplants are increasingly popular. Social workers must assess both the donor and the recipient in order to gauge any normative pressures on donors that may influence the decision to donate a kidney, living donors' motivations for donation, their ability to make an informed consent, the nature of the relationship between donors and recipients, psychosocial status, developmental history, possible substance use, and mental health status (Fisher, 2003; Fox & Swazey, 1979; Leo, Smith, & Mori, 2003).

Findings Indicate That Nephrology Social Work Interventions are Valued and Desired

Family members of dying ESRD patients desire more emotional support and social work interventions and request that social workers make contact with the family after the death (Woods et al., 1999). Siegal, Witten, and Lundin's 1994 survey of ESRD patients determined that almost 91% of respondents "believed that access to a nephrology social worker was important" (p. 33). Dialysis patients have ranked a "helpful social worker" as being the fourth most important aspect of care, more important to them than nephrologists or nurses (Rubin et al., 1997). In one study, more than 84% of patients relied on NSWs for clinical social work intervention to help them improve coping, adjustment, and rehabilitation (Siegal et al., 1994). Seventy percent of patients felt that social workers gave the most useful information about treatment modalities, and that social workers were twice as helpful as nephrologists in deciding between hemodialysis and peritoneal dialysis as treatment modalities (Holley, Barrington, Kohn, & Hayes, 1991).

Support for Appropriate Nephrology Social Work Tasks and Evidence of Misutilization of Master's-Level Social Workers

Russo (2002) found that 100% of nephrology social workers surveyed felt that transportation was not an appropriate task, yet 53% of respondents were responsible for making transportation arrangements. Russo also found that 46% of NSWs were responsible for making transient arrangements, yet only 20% were able to do patient education. Performing tasks such as clerical duties, admissions, billing, and insurance matters prohibit effective nephrology clinical social work interventions for patients (Callahan, Witten & Johnstone, 1997; Russo, 2002). Promoting Excellence in End-of-Life Care (2002), a national program from the office of The Robert Wood Johnson Foundation recommends that dialysis units discontinue using master's-level social workers for clerical tasks (such as arranging transportation) in order to ensure that NSWs have sufficient time for clinical services their patients and families. Merighi and Ehlebracht (2004b; 2004c; 2005), in an exhaustive survey of 809 national NSWs, found that:

- Ninety-four percent of social workers did clerical work (faxing, copying), and that 87% of those respondents found these tasks to be outside the scope of their social work training.
- Sixty-one percent of social workers were solely responsible for arranging patient transportation.
- Fifty-seven percent of social workers were responsible for making transient arrangements, taking up 9% of their entire social work time.
- Only 34% of social workers thought that they had enough time to sufficiently address patients' psychosocial needs.
- Twenty-six percent of social workers are responsible for initial insurance verification.
- Forty-three percent of social workers tracked Medicare coordination periods.
- Forty-four percent of social workers are primarily responsible for completing admission packets.
- Alarmingly, 18% of social workers were involved in collecting fees from patients. This can negatively affect the therapeutic relationship and decrease patient trust.
- The more that NSWs are involved with insurance/billing tasks, the lower their job satisfaction, particularly among social workers who collect fees from patients.
- Nephrology social work job satisfaction is related to the amount of time spent on counseling and patient education (significantly higher job satisfaction) versus insurance-related, clerical tasks (significantly lower job satisfaction).
- Respondents spent 38% of their time on insurance, billing and clerical tasks, versus 25% of their time counseling and assessing patients.
- NSWs who spend more time doing insurance, billing, and clerical activities report more emotional exhaustion.
- NSWs who spend more time doing counseling and patient education report less emotional exhaustion. The authors indicate that these correlations may be indicative of the fact that providing education and direct counseling to patients and family members are activities that are commensurate with the professional training and education of master's-level social workers (unlike billing, insurance and clerical tasks).

Support for Nephrology Social Work/Patient Ratios

NKF's Council of Nephrology Social Workers (NKF-CNSW) recommends 75 patients per full-time social worker. Texas mandates that NSWs have a patient ratio of 75 to 100 patients per full-time social worker (End-Stage Renal Disease Network of Texas, 2001). Social workers report that high caseloads result in a lack of ability to provide adequate clinical services (Merighi & Ehlebracht, 2002). Merighi and Ehlebracht (2004a), in a national survey of dialysis social workers, found that only 13% of full-time social workers had caseloads of 75 or fewer, 40% had case-loads of 76 to 100 patients, 47% had caseloads of more than 100 patients. High nephrology social work caseloads result in lower patient satisfaction and less successful patient rehabilitation outcomes (Callahan et al., 1998). Estrada and Hunt (1998) recommend that increased time is needed for social workers to fully assess patients' psychosocial status. Merighi & Ehlebracht (2005) found that NSWs spend more time providing counseling to patients when they have lower patient caseloads.

In one study of NSWs (Bogatz, Colasanto, & Sweeney, 2005), 68% of all social workers did not have enough time to do casework or counseling; 62% did not have enough time to do patient education; 36% spent excessive time doing clerical, insurance and billing tasks. One participant stated: "the combination of a more complex caseload and greater number of patients to cover make[s] it impossible to adhere to the federal guidelines as written. I believe our patients are being denied access to quality social work services" (p. 59). Social workers in the Bogatz et al. study had caseloads as high as 170 patients; 72% of social workers had a median caseload of 125 patients. Social workers have indicated that large caseloads hinder their ability to provide clinical interventions (Bogatz et al., 2005). For every dollar invested in patient education, $3–$4 were saved in overall healthcare costs (Bartlett, 1995).

Need for Master's-Level Social Work Service Provision in Nephrology Settings

The NSW must be skilled in assessing for psychosocial influences and their interrelatedness in predicting treatment outcomes. The NSW must also be able to design interventions for the patient, the family, the medical team, and community systems at large to maximize the effectiveness of ESRD treatment. The additional training received by master's-prepared social workers enables them to perform these complex professional tasks and ensure effective outcomes that have a direct relationship to morbidity and mortality. Master's-prepared social workers are trained to utilize validated tools, such as the SF36 and KDOQL, to improve care and to monitor the outcomes of directed interventions, assess the complex variables that these instruments measure (Ellstrom-Calder & Banning, 1992; Lenart, 1998; NASW/NKF, 1994), and continually redesign a plan of care to achieve outcome goals. The master's-prepared social worker provides the interdisciplinary team with a biopsychosocial view of the patient's strengths and needs (Berkman, 1996) through use of patient-perceived quality of life (QOL) measures and the person-in-environment model of assessment (Monkman, 1991). Most NSWs provide psychosocial services autonomously as primary providers without social work supervision or consultation. Autonomous practice in an ESRD setting demands highly developed social work intervention skills, obtained through a master's-level curriculum. MSWs are trained to autonomously provide diagnostic, preventive, and treatment services for individuals, families, and groups in the context of their life situations (Harris, 1995). These interventions assist ESRD patients in developing adaptive behaviors and perceptions necessary to cope with the changes brought about by chronic illness and hospitalization.

NSWs must be prepared to contribute to the development of clinical pathways to enhance treatment outcomes. NSWs must have outcome evaluation skills and must understand the interactions among individual systems, the social system, and the medical system as each affects patients and families. NSWs must be able to distinguish between normal adjustment reactions, and more debilitating and potentially self-destructive emotional reactions, as well as tailor interventions to the individual coping styles of the ESRD patient (Christensen, Smith, Turner, Cundick, 1994). The master's in social work (MSW) degree provides an additional 900 hours of specialized training beyond a baccalaureate degree in social work. MSW has the only curriculum that offers additional specialization in the bio-psycho-social-cultural, person-in-environment model of understanding human behavior. Undergraduate (BSW) degrees, or other mental health credentials (MA in counseling, sociology, or psychology, or PhD in psychology, etc.) do not offer this specialized and comprehensive training in bio-psychosocial assessment and interaction between individual and social systems.

The National Association of Social Workers (NASW) Standards of Classification considers the baccalaureate degree as a basic level of practice (Bonner, Dean, & Greenspan, 1989; NASW, 1981). Under these same standards, the master's in social work degree is considered a specialized level of professional practice and requires a demonstration of skill or competency in performance (Anderson, 1986). Empirically, the training of a master's-prepared social worker appears to be the best predictor of overall performance, particularly in the areas of psychological counseling, casework, and case management (Dhooper, Royse & Wolfe, 1990).

The additional 900 hours of specialized, clinical training prepares the MSW to work autonomously in the ESRD setting, where supervision and peer support are not readily available. This additional training in the biopsychosocial model of understanding human behavior also enables the master's-prepared social worker to provide cost-effective interventions, such as assessment, education, and individual, family and group therapy, and to independently monitor the outcomes of these interventions to ensure their effectiveness.

Renal patients present with highly complex needs on individual, as well as systems levels. Social workers are trained to intervene in both of these levels that are essential to optimal patient functioning, and help facilitate congruity between individuals and their environments' resources, demands, and opportunities (Coulton, 1979; McKinley & Callahan, 1998; Morrow-Howell, 1992; Wallace, Goldberg, & Slaby, 1984). Social workers have expertise in combining social context and utilizing community resource information, along with a knowledge of personality dynamics.

NEXT STEPS

As this literature review indicates, we have a rigorous foundation of empirical support for the importance of MSWs in dialysis and transplant settings. In 2019, it is up to all of us to write the next chapter in the history of nephrology social work. We need more social workers to explore how their interventions can affect positive change for patients and systems, and new articles in the *Journal of Nephrology Social Work* and other kidney disease journals, like the ones cited in this literature review. We need to declare the necessity of social work in new ESRD treatment modalities and current expectations in the new kidney disease paradigm of care. What will you do to help make this happen? We encourage you to make this a topic of discussion with your local colleagues, at your local CNSW Chapter meetings, and in your own practice so that you can be a part of the next chapter in nephrology social work history.

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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.

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, & Schiffl, 2009). This is troubling, since ESRD disproportionally 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, & Schiffl, 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

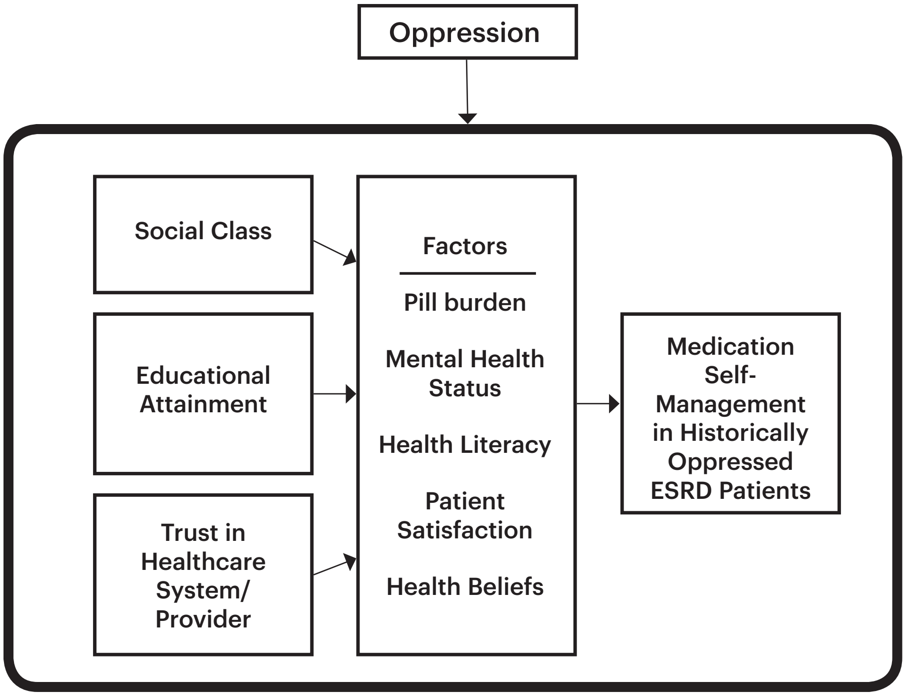
The conceptual model, presented in **Figure 1** below, comprises nine concepts, which influence medication self-management in ESRD patients: *oppression, social class, educational attainment, trust in healthcare system/provider, pill burden, mental health status, health literacy, patient satisfaction, 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, Annagurz, 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 & Schiffl, 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 journies 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, Camancho, 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, Annagurz, 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, Annagurz, 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 realty 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, & Schiffl, 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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Measuring Health-Related Outcomes After a Peer-Led Educational Intervention for African Americans with Chronic Kidney Disease

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There are multiple reasons for the disparity in chronic kidney disease (CKD) among African Americans, including higher rates of diabetes, the absence of disease-specific health knowledge, and unhealthy lifestyle behaviors (eating, exercise). This pilot study measured health-related outcomes of a social worker-coordinated and peer-led psychoeducational program, based on cognitive behavioral therapy (CBT). One-group pretest/posttest was used to measure changes in outcome variables, such as CKD-related health knowledge, healthy lifestyle and behaviors, and medication adherence.

Data from 54 African-American patients indicated statistically significant improvement in scores on the Health Knowledge Scale, but no change in healthy lifestyle and behaviors or medication adherence. Social workers should provide cost-effective and clinically proven psychosocial educational treatments for patients with chronic health conditions. This intervention can be replicated with large, diverse groups in collaboration with other medical professionals.

CHRONIC KIDNEY DISEASE

Chronic kidney disease (CKD) is a primary problem globally and in the United States. The Centers for Disease Control and Prevention (CDC, 2015) ranks CKD as the ninth leading cause of death in the United States. According to the National Kidney Foundation (NKF, 2017), minorities such as African Americans, Hispanics, Asians, Pacific Islanders, American Indians, and Alaska Natives are at the increased for CKD. African Americans are three-times more likely than any other minority group to have kidney failure, compared to White Americans. In a 12-year follow-up cohort study of 9,082 African Americans and Caucasian adults between the ages of 30 and 74 years, African Americans' risk of CKD was 2.7 times higher than that of Whites (Fox et al., 2010). African Americans with an age range between 25 and 44 years have an even higher risk for CKD.

In 2016, there were 124,675 new end-stage renal disease (ESRD) diagnoses, (USRDS, 2018). The occurrence of ESRD has increased to over 20,000 cases per year (Harding et al., 2019; Ishigami & Matsushita, 2018; USRDS, 2018). According to the 2015 USRDS data, the rate of kidney failure differs by race in the United States; thus, African Americans experience ESRD at a three times higher rate than their White counterparts (McCullough, Morgenstern, Saran, Herman, & Robinson, 2019; Saran et al., 2018).

There are multiple reasons for this racial/ethnic disparity, including higher rates of diabetes and hypertension among African Americans. According to the USRDS (2016), African Americans account for 13 percent of the population, but 35 percent of those Americans who are experiencing kidney failure. In fact, African Americans, because of diabetes and high blood pressure, experience kidney failure at a higher level than any other group.

This phenomenon is reflected in the steadily rising incidence of diabetic ESRD among African Americans. African Americans with diabetes have four times the risk of kidney failure, compared to Caucasian Americans (USRDS, 2016). Hypertension, the second leading cause of ESRD, affects one in every three African Americans. For African Americans, the incidence rate of hypertension is listed as the primary cause of ESRD, the incidence of which is dramatically higher than among other racial/ethnic groups (USRDS, 2015).

Other significant reasons for this disparity include the absence of disease-specific health knowledge and unhealthy lifestyle behaviors. Several studies have found that most African Americans are unaware of their increased risk for developing CKD (Vassalotti, Gracz-Weinstein, Gannon, & Brown, 2006; Waterman, Browne, Waterman, Gladstone, & Hostetter, 2008). Although many patients may have a general knowledge of CKD, they cannot know their CKD status or obtain appropriate treatment without testing and communication from their provider (Plantinga, Tuot, & Powe, 2010). In fact, awareness of CKD is limited across all populations. In a survey of urban African American adults, less than 3% named kidney disease as an important health problem, compared with 61% and 55% naming hypertension and diabetes, respectively (Plantinga et al., 2010). Less than one half of those surveyed could define kidney disease, one quarter could name a diagnostic test, and 7% knew that protein in the urine was a sign of kidney disease (Plantinga et al., 2010).

Unfortunately, health lifestyle behaviors, such as poor renal diet, limited physical exercise, and unstable medication adherence are major risks among African-American patients with CKD (Norton et al., 2016). As patients experience kid-

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ney failure, delaying or managing further progression is difficult in most cases. Most people with CKD find it difficult to maintain a well-balanced renal diet (Tsay, 2003). Fluid and salt control are primary causes of elevated blood pressure and expensive emergency room visits.

African Americans also struggle to adhere to guidelines for physical activity and weight management. There are many patients in clinics who are overweight or suffering from obesity at a predialysis stage, on dialysis, or with a transplant (Szromba, 2012). Also, dialysis patients have poor capacity for exercise and self-reported physical functioning, all of which can be potentially ameliorated by exercise training. Reboredo et al. (2010) monitored aerobic exercise training's effect on blood pressure, quality of life, and laboratory results in patients with ESRD being treated with hemodialysis. The study revealed that supervised aerobic exercise training increased physical functioning, contributed to blood pressure control, and improved several quality-of-life measures (Reboredo et al., 2010).

Meanwhile, several studies have shown that only 50% to 60% patients with chronic illness adhere to prescribed medications, regardless of evidence that medication treatment advances life expectancy and quality of life (Bosworth, 2012). Medication nonadherence includes delaying prescription refills, failing to fill prescriptions at all, cutting dosages, or reducing the frequency of administration (Bosworth, 2012). For instance, Lizer, Parnapy, Marsh, and Mogili (2011) explored whether a relationship with a pharmacist-assisted psychiatric clinic would improve adherence to medications and quality of life over six months. Improvements were seen in two domains over the six-month period: physical capacity and psychological well-being (Lizer et al., 2011). Babu, Nagaraju, Prasad, and Reddy (2012) also conducted a study to evaluate medication adherence and quality of life in patients with cholesterol issues. Patients who were adherent to their cholesterol medications reported a better quality of life regarding social activities. It was concluded that nonadherence to medications was prevalent in the study groups, but on the lower side of the range; adherent patients had higher quality of life (Babu et al., 2012).

PEER-LED PSYCHOEDUCATIONAL INTERVENTION

Few, if any, studies have investigated the effectiveness of peer-led support as a means of increasing health knowledge and decreasing negative health lifestyle behaviors in African Americans with CKD. In fact, peer-led support has been effective in patients with cancer, diabetes, heart disease, depression, HIV/AIDS, multiple sclerosis, brain injury, and several other health conditions (National Kidney Foundation, 2012; Tang, Funnell, Sinco, Spencer, & Heisler, 2015; Taylor, Gutteridge, & Willis, 2015). The peer-led models of education are known to be vital to improving health awareness and health behavior in patients with other chronic diseases (Beck, Greenwood, & Blanton, 2018).

Studies have established the effectiveness of peer-led support on illness by using self-management coaching interventions in patients recently diagnosed with type 2 diabetes (Wulp, De Leeuw, Gorter, & Rutten, 2012). Wulp et al. (2012) found that peer-led self-management coaching programming for patients recently diagnosed with type 2 diabetes improved self-efficacy in patients who had experienced low self-efficacy shortly after diagnosis. Long, Jahnle, Richardson, Loewenstein, and Volpp (2012) studied veterans with diabetes to determine whether peer counselors or financial incentives were better than the usual care in helping African-American veterans to decrease their hemoglobin A1C (HbA1c) levels. Results indicated that mentors and mentees placed the most telephone calls in the first month, with calls decreasing to a mean of two in the sixth month (Long et al., 2012). Levels of HbA1c decreased from 9.9% to 9.8% in the control group, from 9.8% to 8.7% in the peer-mentored group, and from 9.5% to 9.1% in the financial incentive group. Mean change in HbA1c levels from the beginning of the study to 6 months was 1.07% (95% CI, 1.84% to 0.31%) in the peer-mentored group and 0.45% (95% CI, 1.23% to 0.32%) in the financial incentive group (Long et al., 2012). The overall results indicated that peer counselors improved glucose control in the cohort of African-American veterans with diabetes.

Harris and Larson (2007) explored the effectiveness of peer-led support counseling from the perspective of 12 participants living with HIV who had had experiences with peer counseling. Results showed that peer counseling helped participants to discover, refine, and embrace hope after having received a diagnosis of HIV, rather than spending time trapped in a high-risk lifestyle. Participants reported that peer counselors listened to and validated them, helping them to deal with the emotions of living with HIV (Harris & Larson, 2007). Participants in the study perceived peer counselors as experienced, given their personal backgrounds regarding HIV and connected issues (e.g., being gay or having experienced a high-risk lifestyle).

Peer support has also been shown to be effective for patients with CKD (NKF, 2012). For instance, Perry et al. (2005), in a controlled randomized intervention study with 203 patients, explored the impact of peer counselors on end-of-life decision making in CKD. Results showed that peer mentoring significantly influenced completion of advanced directives, compared with distributing standard printed materials. The influence was more pronounced in African Americans. According to the study, apart from increasing the use of advanced directives, the patients' overall well-being was increased as well.

Perry, Swartz, Kelly, Brown, and Swartz (2003) reported that the Robert Wood Johnson Foundation (RWJF) investigated and developed resources to help renal teams to improve palliative care for CKD patients. RWJF found that peer mentoring provided excellent, cost-free support. Repper and Carter's (2011) review of the peer-led support literature in mental health services showed that peer support could lead to a reduction in hospital admissions with a concomitant reduction in workload for medical staff, as well as a reduction of healthcare costs.

Peer-led support also assisted the healthcare system in reaching otherwise hard-to-engage populations. Peer support leads to improved outcomes for clients, such as increased community connections, decreased hospitalization, improved quality of life, and improved social functioning (Moll, Holmes, Geronico, & Sherman, 2009).

Although peer-led support is an effective approach to managing chronic disease, it remains largely unexplored regarding increasing health knowledge and improving health behaviors in patients with CKD. The main objective of this study was to measure health-related outcomes after implementing a social worker-coordinated peer-led educational intervention for African Americans with CKD.

METHOD

Design

This pilot study used a one-group pretest/posttest design (O1 X O2). With relatively low internal validity, the pre-experimental design assesses selected outcome variables before and after an intervention but does not attempt to control for alternative explanation of any changes in scores that are observed (e.g., Rubin & Babbie, 2017). This design may be commonly found in the evaluation of the effectiveness of social services in order to demonstrate desired outcomes before and after services are delivered. Although this design may sound more feasible and scientifically acceptable in social work practice by assessing causal time order, it does not account for factors other than the intervention variable that might have caused the change between pretest and posttest results. Factors usually associated with threats to internal validity include history, maturation, testing, and statistical regression. In spite of empirical merits and practical application in social work practice, this pre-experimental design can be inferior to true experimental designs with randomization and control groups.

Participant Recruitment

The state of Mississippi has growing numbers of patients who have CKD. In a study conducted in Mississippi and released in January 2009, only about one in six African Americans in Mississippi with CKD were aware of having the condition (Flessner et al., 2009). The Leonard Morris Chronic Kidney Disease Leadership Task Force of the Mississippi State Department of Health (2010) states that many Mississippians were unware of having kidney disease, which could lead to ESRD. African Americans accounted for about 67% of these people.

This pilot study recruited participants with CKD and regular attendees at the University of Mississippi Medical Center (UMMC) Renal Clinic in Jackson, MS. The clinic on average serves approximately 700 patients; all were regularly followed. The study sample size was considered adequate to power a level of .80 and alpha level of .05 (confidence level 95%; Fowler, 2009). Study participants were selected as they came for clinic visits. Eligibility criteria for the pilot study were: a) African American; b) in Stages 2 to 4 of kidney disease; c) 20 to 65 years old; d) attending the designated renal clinic; and e) well enough to participate in 30–60 minutes of a face-to-face counseling session.

The project coordinator presented an information sheet describing the project scope and purpose to potential participants. The University of Mississippi Medical Center Institutional Review Board (IRB) approved the intervention pilot study with human subjects. Patients were enrolled into the study only with fully informed consent. Eighty-three patients participated in the intervention study at baseline.

Intervention Implementation

The study hired three paid African American patients referred to as “peer counselors” to deliver the intervention. Peer counselors, recommended by providers, were transplant patients who had experienced chronic kidney disease and were considered model patients. A research coordinator, the social worker from the UMMC clinic trained and supervised three peer counselors. Peer counselor training included general kidney disease information about blood pressure, diabetes, diet, exercise, adherence, and self-efficacy skills.

The goals of this peer-led psychoeducational intervention were to: a) increase kidney-specific health knowledge, and b) change patients’ health behaviors and lifestyle. The intervention procedures were divided into two six-month intervals (Phases I and II) over the span of a year. In Phase, I, the intervention sessions, consisting of components of individual and group counseling, were delivered either by phone or in face-to-face meetings. Individual or group sessions were held in the renal clinic examination rooms, social work office, or conference rooms. Each session lasted for approximately 45–60 minutes. Several telephone follow-ups were implemented to reinforce patient learning on kidney disease and healthy lifestyle practices (e.g., food/diet, exercise, medication adherence).

Since CKD is a slowly and progressive deterioration of kidney function that is typically irreversible, participants were scheduled for one or two visits in six months (Moodalbail & Hooper, 2017). During Phase I, the clinic nurse scheduled the initial visits; additional appointments were arranged by the peer counselors and renal clinic social worker. Participants who did not show for a scheduled visit received a call from one of the peer counselors. In addition to their required two regular visits, participants were encouraged to attend four other unscheduled visits and also had a weekly telephone support call. The weekly telephone calls were both supportive and educational. **Table 1** shows the psychoeducational topics that were discussed on each visit and in weekly follow-ups. The second six-month interval (Phase II) followed the same structure and served as a reinforcement of what was discussed in the first six months.

At the first individual session of the first six-month interval (Phase I), peer counselors introduced themselves, explained the process of the intervention, and outlined for the participant the contents of the kidney education and types of skills that the participant was expected to gain. The peer counselors described the telephone support system and what was expected of each patient. In the second session, peer counselors and participants discussed personal thoughts, emotions, and health behaviors, using the plan and goal sheet. This session also allowed participants to gain insight into possible cognitive distortions that could negatively affect self-regulation and ultimately affect health behaviors. This session involved teaching participants about self-efficacy through peer counseling and reinforcing positive behavior through demonstration.

The third to sixth "unscheduled" sessions followed the same structure to promote the use of a home blood pressure monitor, a diabetes monitor, a blood pressure and diabetes log, a telephone education and support log, and educational pamphlets on sodium and fluid restriction. These support materials empowered participants to take personal responsibility for monitoring their health. Participants were asked to monitor and record their physical activity, as well as salt and fluid intake at home. They were also asked to record reasons why they were unable to control their blood pressure or salt and fluid intake, based on real-life experiences. The research coordinator reviewed participant records on a weekly basis to determine who needed further assistance.

While peer counselors communicated with participants by telephone, they also led group sessions. Peer counselors facilitated group discussions and role-playing among participants and encouraged attendees to educate each other on kidney disease management. Participants hosted a health fair to display what they had learned in the educational sessions. For example, participants wore tee shirts with the inscription “Ask Me about Kidney Disease.” Peer counselors hosted an interactive public event to educate participants’ families on the education that the participants had received. Weekly followups by telephone offered alternative solutions for participants who needed further assistance to achieve their goals. Examples of discussions with participants included: offering advice related to substitutions for salt and fluid intake, and addressing nonadherence to blood pressure medications, dietary routine, and physical activities.

OUTCOME MEASURES

Health Knowledge Scale: The Health Knowledge Scale (**Table 5**) is a 10-item instrument designed to measure patient knowledge about kidney disease. Participants were asked to respond “True” or “False” to 10 statements. Four items (1, 3, 4, 10) should be answered False, and 6 items (2, 5, 6, 7, 8, 9) should be answered True. Correct answers were recoded as 1, and a wrong answer as 0, with higher scores indicating greater knowledge. Total scores could range from 0 to 10. **Table 3** includes the full statements with correct answers.

Health Lifestyle and Behaviors Scale: The questions asked in this instrument related to specific items defining kidney health behaviors that affect quality of life. The instrument addressed three major components: daily nutritional habits, physical activities, and medication adherence (see **Tables 4** and **5**). The first section, regarding renal diet, included questions such as “How many meals do you eat in a normal day?”, “How often do you eat vegetables?”, and “How often do you eat chips, dip, or extra salt?” The desired answers were coded as: 1 = healthy eating habits and 0 = unhealthy eating habits. Summed scores could range from 0 to 10, with higher scores indicating healthier lifestyles.

The second section contained three questions about physical activities: In a week, 1) “Do moderate activities for at least 10 minutes at a time?" (such as brisk walking, vacuuming, gardening, or minimal change in breathing or heart rates); 2) "Do you do these moderate activities more than 3 days per week for at least 10 minutes?"; and 3) "Do vigorous activities for at least 10 minutes at a time?" (such as running or any stronger activities that causes increase in breathing or heart rates). Desired physical activities were coded 1; summed scores ranged from 0 to 3, with higher scores indicating healthier lifestyles.

The third section addressed medication adherence. Reasons for not taking medications properly were listed in 15 statements, such as “You were in a hurry, too busy, or forgot”; “It was inconvenient”; “The medication made you feel bad”; or “You missed medications because you were feeling better.” “Yes” answers were scored 1, and “No” answers were scored 2, with higher scores indicating more positive medication compliance.

Data Analyses

The statistical analyses were conducted using version 25.0 of the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were used to describe the participants’ demographic information, such as gender, age, education, annual income, and health insurance. Descriptive statistics with mean and standard deviation were used to measure health-related outcomes, and *t*-tests were conducted to compare group mean score differences from pretest to posttest regarding individual items and summed scores for each scale.

RESULTS

Table 2 displays sociodemographic characteristics of intervention participants. The majority were female (*n* = 35; 65%) and 51 to 70 years old (*n* = 30; 56%). Educational levels were fairly equally distributed, but 33% (*n* = 18) had not completed high school. Most participants (*n* = 35, 65%) reported their income from $5,000 to $9,999, and most participants were insured by Medicare or other insurance (private or Medicaid), with only 8 persons uninsured.

Table 3 presents descriptive statistics of individual item scores and summed scores for the Health Knowledge Scale, with *t*-values and statistical significance. The mean pretest score was 4.70 (*SD* = 1.25) in a total possible score of 10, indicating that this sample had limited knowledge about kidney disease before attending the educational sessions. A year later, the knowledge score had improved significantly to a statistical mean of 7.44 (*SD* = 2.21). When summed scores were compared, the paired-sample *t*-values was -4.72, significant at $p < .001$. Scores on five items requiring specific medical knowledge were not significantly changed in the posttest.

Table 4 shows results of the Health Lifestyle and Behavior Scale. There was no statistically significant improvement in group mean scores for the renal diet category from pretest (*M* = 5.48; *SD* = 1.63) to posttest (*M* = 5.34; *SD* = 2.13). This result indicated that all participants maintained mixed eating habits. The level of physical activity improved slightly, but was not statistically significant (*M* = 1.04 versus *M* = 1.17).

Table 5 presents the descriptive statistics for 15 statements related to medication adherence. "Yes" answers indicated medication noncompliance, with higher scores indicating greater noncompliance. Mean score differences were found for a few items, such as "You don't like to take medication"; "If you took the medication, you would not be able to carry out your normal activities, for example, driving"; and "You missed medications because you were feeling better." The overall score was changed, (*M* = 26.94, *SD* = 2.72 versus *M* = 27.12, *SD* = 3.75) but the difference was not statistically significant.

DISCUSSION AND IMPLICATIONS

This pilot study showed limited improvement in health-related outcomes such as CKD-related health knowledge, healthy eating habits and physical activity, and medication adherence. Health knowledge significantly improved from pretest to posttest. However, most participants gave incorrect answers to three items about medical diagnostic symptoms, when it was expected that they would demonstrate full understanding of CKD symptoms, diagnosis, and treatment. Except for several single items, there were no statistically significant changes in group mean differences for the three health-related outcome measures. The year-long psychoeducational intervention was expected to show positive changes in lifestyle and behaviors. Factors that might have contributed to the failure to realize significant differences included difficulties with participant retention, a smaller sample in posttest compared to pretest due to attrition, and the simpler nature of the "Yes"/" No" answer options on certain items.

The study results provide practical lessons for social workers in healthcare settings. First, the study was an attempt to implement a feasible peer-led psychoeducational intervention. The primary author, Katina-Lang Lindsey, PhD, LMSW, a licensed social worker, trained potential peer counselors and coordinated the funded program. As a key member of the interdisciplinary research team, the social worker incorporated social cognitive therapeutic skills into the educational intervention manual. She played a critical role as a research coordinator in recruiting and retaining participants and maintaining the quality of program delivery. Further, the social worker engaged in data collection and analysis, with assistance from statistical consultants.

This study also addressed the need for social work students to prepare to work with chronic disease-specific clients, such as those with diabetes or heart disease or kidney failure. As many social workers serve as members of interdisciplinary teams, they must have the disease-specific knowledge, skills, and techniques to work with patients with chronic illness in the healthcare system.

This study focused on African Americans in a disadvantaged socioeconomic situation, because underserved minority patients are often hard to reach. As advocates for vulnerable clients, such as CKD patients in disadvantaged socioeconomic states, social workers should provide cost-effective and clinically supported treatment options for these patients. Doctors and nurses treat CKD patients with medications, therapies, or surgery. Social workers, through intimate individual or group counseling, can educate CKD patients about their disease and about how to change their behaviors and lifestyles. Because of mistrust of the healthcare system by minority populations, same-race/ethnic peer counselors or educators could deliver treatment or implement clinical interventions.

This research presents a paradigm shift in researching unconventional interventions by social workers. Social workers have been overlooked as credible actors for designing, and implementing, as well as working directly with participants in, clinical intervention studies. There has been a perception that social workers are self-limited to conducting individual psychosocial assessment in clinical settings, not attempting to expand their skills and knowledge to intervention research activities. Now, social workers are beginning to change the atmosphere for implementing experimental or even mixed-methods designs. Futher, it is important that social workers design interventions that are grounded in evidence-based social work practice (EPB). Despite the national emphasis on social work research, EBP-based curricula have not been commonly adopted in many schools of social work. EBP has been considered to be a new paradigm for both social workers practicing research and in education (Kawam, 2015). Primarily, social work researchers and educators have tended to embrace the concept of a systematic approach to EBP, as schools of social work have begun to integrate EBP into curricula (Kawam, 2015).

Several inherent limitations should be noted. Peer educators have been vital in the intervention study. Timely recruitment and training time for peer counselors were as expected. However, in mid-intervention, one male counselor dropped out, which may have negatively affected the quality of program delivery. Turnover in staff and members of the research team affected study flow and the intervention itself. Another problem came from the newly developed measures (e.g., Health Lifestyle and Behaviors Scale). The "Yes"/" No" answer choice created a dichotomous variable with less score variability, increasing the difficulty of finding significant statistical group differences in this small sample size. These measures were used without testing them for reliability and validity. Measurement issues among primary outcome variables may have contributed to the failure to find significant relationships among variables. The scales were not validated with minority populations from disadvantaged socioeconomic situations. Natural attenuation in participation can be an issue in most intervention studies.

There is need for continued advocacy for people with CKD. CKD and ESRD are among the only chronic illnesses with legislation to support patients with the debilitating diseases. The study results show an urgent need for social workers to be involved in the treatment process to improve CKD patients' health-related quality of life. More nephrology social workers are needed in key roles in healthcare practice and legislative/policy advocacy. Social work students or practitioners in medical settings should obtain more knowledge about effective psychosocial, and educational interventions for patients with chronic illness. Social work practitioners should recognize populations that are disproportionately affected with CKD, and find ways to improve their well-being. Social workers can be better-informed practitioners and researchers, providing empirical evidence for research from their clinical workplaces.

Social work practitioners and researchers should continue to further explore peer-led educational interventions that have been successful for other chronic illnesses. Future research can be improved by adding more diverse clients, selecting well-tested measures, and implementing methodologically solid data collection procedures, such as repeated measures (pre-/post-/follow-up). By securing more research funding, social work researchers could implement a broader experimental study of this type.

Social workers need to continue to get involved with community-based interdisciplinary research teams as highly trained practitioner-researchers. They can provide more theory-based, in-depth training using cognitive behavioral theory for peer interventions throughout the kidney healthcare field. CKD social workers can replicate this intervention design with large, diverse populations, particularly in collaboration with other medical disciplines. Moreover, social work researchers need to participate in large, funded research projects on this subject to produce scientific evidence applicable to clinical practice. Peer-led psychosocial educational interventions hold a great deal of potential for the field and patients. While there is a need for scientific inquiry and clinical practice, there also a need to improve peer interventions. This is of great importance and holds a great deal of potential for the field of social work and patients nationally.

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Table 1. Module topics, delivery methods, and follow-up

Module topics	Delivery methods	Telephone follow-up
General health and kidney-specific disease education	Peer-led session (45–60 minutes)	September: Supportive education
Individual plan for kidney education	Peer-led session (45–60 minutes)	October: Supportive education
Promote blood pressure management and self-efficacy skills	Peer-led session (45–60 minutes)	November: Supportive education
Promote diabetes management	One group session led by social worker	December: Supportive education
Promote healthy diet/exercise and lifestyle change	Peer-led self-efficacy training	January: Supportive education
Promote adherence and self-efficacy skills	Two group sessions led by social worker and peer counselor	February: Supportive education

Table 2. Sociodemographic characteristics of participants in intervention group

Variable	Categories	Pretest (*n* = 54)	Posttest (*n* = 27)	Valid *n*	χ^2
Gender	Female	35 (64.8)	21 (77.8)	56	.167
	Male	19 (35.2)	6 (22.3)	25	.006*
Age	20–30	5 (9.0)	2 (7.4)	7	.571
	31–40	2 (3.7)	0 (0.0)	2	.053
	41–50	13 (24)	8 (29.6)	21	.013*
	51–60	18 (33.3)	6 22.2)	24	.019*
	61–70	12 (22.2)	7 (25.9)	19	.890
	> 70	4 (7.4)	4 (14.8)	8	.671
Education	8th grade or less	6 (11.1)	7 (25.9)	13	.510
	Some HS or less	12 (22.2)	7 (25.9)	19	.251
	HS or GED	17 (31.5)	5 (18.5)	22	.049*
	Some college	12 (22.2)	6 (22.2)	18	.038*
	College degree	7 (13.0)	2 (7.4)	9	.147
Annual Income	< $5,000	3 (5.6)	4 (14.8)	7	.957
	$5,000 ~ $9,999	35 (64.8)	16 (59.3)	51	.010*
	$10,000 ~ $19,999	7 (13.0)	7 (25.9)	14	.870
	$20,000 ~ $40,000	3 (5.6)	0 (0.0)	3	.118
	Don't know	6 (11.1)	0 (0.0)	6	.155
Insurance	Uninsured	8 (14.8)	2 (7.4)	10	.145
	Medicare only	11 (20.4)	3 (11.1)	14	.003 *
	Medicare & any other ins.	13 (24.1)	13 (48.1)	26	.429
	Medicaid or Medi-Cal only	14 (25.9)	9 (33.3)	23	.697
	Private, fee for service	4 (7.4)	0 (0.0)	4	.033 *
	HMO, PPO, IPA, etc.	4 (7.4)	0 (0.0)	4	.016

Table 3. Change in health knowledge scale with paired-sample *t*-test

#	Questions	Answer	Pretest	Posttest	*t*-value
	Kidney Disease Health Knowledge		**0 ~ 1**	**0 ~ 1**	
1.	Your kidney's only job is to remove wastes and excess fluid from your body.	False	.53 (.51)	.63 (.49)	-.527 (ns)
2.	People with diabetes or high blood pressure have/are more likely to get chronic kidney disease.	True	.36 (.48)	.73 (.45)	-1.809 (ns)
3.	People with chronic kidney disease always have a lot of symptoms.	False	.07 (.25)	.64 (.48)	-5.196 ***
4.	African Americans have a low risk of developing chronic kidney disease.	False	.09 (.29)	.50 (.51)	-3.166**
5.	Chronic kidney disease can be found with simple blood and urine tests.	True	.86 (.35)	.80 (.41)	.700 (ns)
6.	Early detection and treatment can often keep chronic kidney disease from getting worse.	True	.69 (.47)	.84 (.37)	-2.313 *
7.	Persistent protein in the urine is an early sign of chronic kidney disease.	True	.78 (.42)	.89 (.32)	.000 (ns)
8.	The best way to know how your kidneys are working is to know your glomerular filtration rate (GFR).	True	.36 (.48)	.89 (.32)	-2.828 **
9.	Anemia and bone disease are common problems for people with chronic kidney disease.	True	.36 (.48)	.73 (.45)	-1.809 (ns)
10.	People with chronic kidney disease have a low risk of getting heart disease.	False	.62 (.49)	.69 (.47)	-2.021 *
Sum.	**Total Score Mean (SD)** [Range from 0 to 10]		**4.70 (1.25)**	**7.44 (2.21)**	**-4.72*** **

Note: ns = not significant. **p* < .05 ***p* < .01 ****p* < .001

Table 4. Difference in renal diet, eating habits and physical activities with paired-samples *t*-test

#	Health Lifestyle and Behavior Scale Questions Renal Diet	Correct responses (healthy = 1)	Pretest *M*(*SD*)	Posttest *M*(*SD*)	*t*-value
1.	How many meals do you eat in a normal day?	3 meals a day	.57 (.501)	.52 (.505)	-.901
2.	Do you usually eat breakfast?	Yes, I eat breakfast.	.77 (.424)	.81 (.394)	-.296
3.	How often do you eat between meals?	Rarely	.18 (.390)	.27 (.451)	-1.141
4.	How often do you drink fruit juice?	Less than every week	.30 (.462)	.30 (.462)	.000
5.	How often do you eat fruit?	At least once a day	.41 (.497)	.50 (.506)	-.327
6.	How often do you eat vegetables?	At least once a day	.47 (.505)	.30 (.462)	1.445
7.	How often do you eat chips, dip, or extra salt?	Less than every week	.67 (.477)	.77 (.427)	.000
8.	How often do you read labels on food?	Always	.47 (.505)	.52 (.505)	-.492
9.	To lower your risk of worsening HBP or KD are you eating less salt?	Yes, I eat less salt.	.90 (.297)	.86 (.354)	.811
10.	Have you made major changes for health reasons?	Yes, I made major health changes.	.88 (.324)	.84 (.370)	.371
Sum	**Total Score Mean (SD) [0–10]**		**5.48 (1.633)**	**5.34 (2.128)**	**.517 (ns)**
	Physical Activity Statement	**(coded as 1)**			
1.	Do moderate activities for at least 10 minutes at a time?	Yes	.49 (.506)	.44 (.502)	.000
2.	Do you do these moderate activities more than 3 days per week for at least 10 minutes at a time?	Yes	.72 (.461)	.85 (.366)	1.000
3.	Do vigorous activities for at least 10 minutes at a time?	Yes	.10 (.307)	.19 (.397)	-1.000
Sum.	**Total Score Mean (SD) [0–3]**		**1.044**	**1.174**	**.684 (ns)**

Note: ns = not significant. *p <.05. **p < .01. ***p < .001

Table 5. Reasons for medication noncompliance

	Medication Adherence (Reasons for Noncompliance)	**Pretest *M*(*SD*)**	**Posttest *M*(*SD*)**	**No = 2**	***t*-value**
1.	You were in a hurry, too busy, or forgot.	1.64 (.490)	1.80 (.408)	Yes	-1.163 *
2.	It was inconvenient.	1.71 (.464)	1.75 (.442)	Yes	-.272
3.	The medication would not do you any good.	1.74 (.449)	1.78 (.422)	Yes	-.327
4.	The medication made you feel bad.	1.78 (.422)	1.65 (.487)	No	.901
5.	If you took the medication, you wouldn't be able to carry out your normal activities; for example, driving.	1.88 (.338)	1.63 (.495)	No	2.015**
6.	You thought you might become addicted or hooked on the medication.	1.74 (.449)	1.78 (.422)	Yes	-.327
7.	You don't like to take medication.	1.91 (.288)	1.65 (.487)	No	2.021**
8.	You were trying to do without it.	1.78 (.422)	1.74 (.449)	No	.327
9.	You did not have the money to purchase the medication (or its refills).	1.58 (.504)	1.46 (.509)	No	.901
10.	You did not have the medication available; for example, you left it at home or it was not with you.	1.71 (.464)	1.58 (.504)	No	.901
11.	You ran out of the medications.	1.46 (.509)	1.58 (.504)	Yes	-.827
12.	You missed medications because you were feeling better.	1.95 (.213)	1.82 (.395)	No	1.368*
13.	You missed medications because you felt sick.	1.91 (.294)	1.77 (.429)	No	1.142
14.	You took someone else's medications.	1.82 (.395)	1.82 (.395)	~	.000
15.	Are there any other reasons why you haven't taken a prescribed medication?	1.90 (.308)	1.90 (.308)	~	.000
Sum	**Total Score Mean (SD)** [Score range from 15 to 30]	26.94 (2.72) 17 ~ 30	27.12 (3.75) 16 ~ 30		

Notes: The lower score indicates less compliance and the higher score means more in compliance.

National
Kidney
Foundation®

2020
SPRING
CLINICAL
MEETINGS

SAVE THE DATE

Meeting Dates March 25 – 29, 2020
Ernest N. Morial Convention Center
New Orleans, LA

nkfclinicalmeetings.org

People are waiting for a chance at a better life. The kidney transplant waiting list is getting longer, and in response, the National Kidney Foundation (NKF) has developed THE BIG ASK: THE BIG GIVE. This initiative educates and raises awareness about living kidney donation and transplantation among kidney patients, their families, and friends.

THE BIG ASK

For people with kidney disease, asking someone to consider donating a kidney can seem impossible. Many won't get a transplant because they don't know how to ask or are uncomfortable with asking. NKF provides suggestions and tips on how to start a conversation about the possibility of donation.

THE BIG GIVE

The decision about whether to donate a kidney can be daunting. People considering living donation have many questions about what's involved. NKF offers factual, unbiased information addressing common concerns, and support in making the decision.

National
Kidney
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NKF Cares Help Line—Trained professionals answer questions and provide confidential, one-on-one support to patients, families, and potential donors. Hours: Monday–Friday, 9:00am–5:00pm EST (English/Spanish). 844.2BIGASK (844.224.4275); bigask@kidney.org.

www.kidney.org/livingdonation—NKF's website provides information for kidney patients and potential donors.

#BigAskBigGive

National
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