# 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; lifethreatening 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, Zirovanis, 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-

Corresponding author: Teri Browne, PhD, MSW, Editor of the *Journal of Nephrology Social Work*; brownetm@mailbox.sc.edu; 803.777.6258

10

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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