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The Journal of Nephrology Social Work

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The Journal of Nephrology Social Work

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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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The Journal of Nephrology Social Work is always interested in attracting talented CNSW members to serve as Editorial Board members to help with the planning, solicitation, and review of manuscripts for publication.

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The Journal of Nephrology Social Work (*JNSW*) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate research and interest in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. *JNSW* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

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TYPES OF MANUSCRIPTS BEING SOUGHT

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Practical Aspects Section. Contributions to this section are detailed protocols, forms, or other such materials that are successfully utilized for delivery of outcomes-based clinical social work services.

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3) Text
4) References
5) Appendices (optional)
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Substance Use Disorders and Kidney Disease:

Implications for Nephrology Social Work Practice ⅄

Teri Browne, PhD, MSW, NSW-C; Kristen D. Seay, PhD, MSW; Aidyn Iachini, PhD, MSW; Dana DeHart, PhD, MA; Stephanie Clone, MSW; Caroline Pantridge, MPH; Aliza Petiwala, MSW, MPH, University of South Carolina College of Social Work, Columbia, SC

Substance use disorders (SUDs) are a public health issue as well as a significant psychosocial barrier resulting in chronic kidney disease outcomes such as mortality and morbidity. Nephrology social workers need a general understanding of SUDs, SUD issues pertinent to patients with kidney disease, and best practices for working with such patients and their family members. This article provides an overview of SUDs, details SUD-related conditions in kidney disease populations, discusses implications for nephrology social work practice, and makes recommendations for such care.

INTRODUCTION

Nephrology social workers are the behavioral health specialists of dialysis and kidney transplantation interdisciplinary teams, and play a critical role in helping patients with kidney disease ameliorate psychosocial barriers to optimal outcomes. Existing barriers to care include substance use disorders (SUDs), the use of excessive alcohol/prescription medication and/or illegal drugs (Substance Abuse and Mental Health Services Administration (SAMHSA), 2015a). Nephrology social workers could benefit extensively from knowledge about SUDs, an understanding of issues relevant to kidney disease patients with comorbid SUDs, and interventions that can be useful for this population. This article reviews these subjects and can help inform and improve social work practice in nephrology settings.

SUBSTANCE USE DISORDERS—A PUBLIC HEALTH CRISIS

SUDs are a worldwide public health issue, with significant prevalence and health consequences. Internationally, alcohol use is one of the top five greatest risk factors for disease, disability, and death (World Health Organization (WHO), 2011). In the United States, 8% of the general population has an SUD (SAMHSA, 2013). About one out of ten (10.2%) Americans over the age of 12 engaged in illicit drug use during a given past month (Center for Behavioral Health Statistics and Quality (CBHSQ), 2015). An estimated 23% of Americans 12 and older reported binge alcohol use (5 or more drinks) on at least one occasion in the past month (CBHSQ, 2015). Among individuals who consume alcohol, 43.6% reported binge alcohol use (CBHSQ, 2015).

SUDs affect all demographic groups across the life span. The Substance Abuse and Mental Health Services Administration (SAMHSA, 2015b) of the U.S. Department of Health and Human Services reports that:

- 8.8% of adolescents aged 12–17 (an estimated 2.2 million adolescents) reported using illicit drugs.
- 6.2% of U.S. adolescents (an estimated 1.6 million adolescents) were binge alcohol users.
- Young adults (aged 18–25) had the highest percentage of alcohol dependence (13.0%) and illicit drug dependence (7.4%).
- 6.7% of persons aged 21 or older (an estimated 15.1 million individuals) report heavy alcohol consumption.

The individual and social consequences of SUDs make attention to this social problem a priority. For example, in March 2016, President Obama created a Mental Health and Substance Use Disorder Parity Task Force to launch a national effort to address SUDs (The White House, Office of the Press Secretary, 2016). Efforts such as these, including coverage for SUD treatment in the Affordable Care Act, highlight the significance of SUDs (Andrews, Grogan, Brennan, & Pollack, 2015).

SUBSTANCE USE DISORDERS AND KIDNEY DISEASE

Given the prevalence of SUDs, it is no surprise that this is an area of significance and concern for kidney disease populations. SUDs can directly and independently lead to acute kidney injury (AKI) and end-stage renal disease (ESRD) (Bickel et al., 2013; Buettner et al., 2014; do Sameiro Faria, Sampaio, Faria, & Carvalho, 2003; Kumar & Vasudevan, 2008; Singh, Singh, & Jaggi, 2013; Vupputuri et al., 2004; Zielezny, Cunningham, & Venuto, 1980), as well as play a role in contributing to chronic kidney disease (CKD) (Epstein, 1997; Hennessy, 2015; Kazancioğlu, 2013; Mocroft et al., 2015). For example, heroin use may lead to AKI as well as heroin-associated nephropathy that leads to ESRD (Howse & Bell, 2011). Individuals who have used heroin or other opiates have significantly higher risk for ESRD (Perneger, Klag, & Whelton, 2001). Intravenous drug use (Jung et al., 2012) and "skin popping" (injecting drugs directly into the tissue

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⅄ Earn ASWB credit for this article through NKF's Professional Education Resource Center at http://education.kidney.org/JNSW-CE-Program under the skin) of drugs can result in renal AA-amyloidosis, which can progress to CKD (Lejmi, Jen, Olson, James, & Sam, 2015). Bautista and colleagues (2015) determined that a heroin overdose was responsible for AKI due to heroin crystallization in the renal tubules. Bohatyrewicz and colleagues (2007) report a case study in which they conclude that a kidney transplant patient developed his renal failure due to membranous glomerulonephritis associated with heavy marijuana abuse. “Bath salts” crystal use (Adebamiro & Perazella, 2012) and “designer” or synthetic drug use are also associated with AKI (Luciano & Perazella, 2014; Pendergraft, Herlitz, Thornley-Brown, Rosner, & Niles, 2014).

Cocaine use is associated with exacerbated hypertension severity, leading to AKI and ESRD (Buettner et al., 2014; Dunea, Arruda, Bakir, Share, & Smith, 1995; Goel, Pullman, & Coco, 2014; Norris et al., 2001; Rossi et al., 2016; Sánchez, Pérez, Romero, & Lorman, 2010). Interestingly, Fine and colleagues (2007) discovered that cocaine use by individuals with HIV can lead to hypertensive renal changes, even in the absence of hypertension. Methamphetamine use is linked to severe hypertension and kidney failure (Jones & Rayner, 2015). Alcohol use is related to an increase in gout in CKD patients (Jing et al., 2015).

SUDs also can be indirectly associated with ESRD. Individuals with hepatitis C are significantly more likely to consume alcohol and drugs, and have ESRD (Basseri et al., 2010; Li et al., 2014). In particular, intravenous drug use by individuals with hepatitis C may lead to AKI (Satapathy, Lingisetty, & Williams, 2014).

The relationship between SUDs and all stages of kidney disease is internationally relevant, and affects some of the most vulnerable populations with CKD and ESRD. Steele, Belostosky, and Lau (2012) discuss the unique ramifications of SUDs for adolescents with CKD, and suggest that “the deleterious effects of drug abuse on the kidney, especially in patients with pre-existing renal insufficiencies, cannot be overemphasized" (p. 19). The authors recommend that all adolescent CKD patients be screened for SUDs.

The literature also highlights the impact of SUDs among patients who are homeless, impoverished, and older. These individuals may be more susceptible to SUDs as well as comorbid conditions (such as diabetes and hypertension), due to the cumulative health risks from their life experiences and psychosocial stressors. For example, Garcia-Garcia and colleagues (2013) found that individuals who had CKD and who were experiencing homelessness in Mexico were significantly more likely to have an SUD. A study in Canada found that 45% of the individuals in their study of CKD and homelessness had alcohol or drug addictions (Podymow & Turnbull, 2013).

Similar findings about the issue of SUDs in CKD patients experiencing homelessness in the U.S. suggest that a history of SUDs significantly increases the risk of ESRD and death, as well as the use of acute care services (Hall, Choi, Himmelfarb, Chertow, & Bindman, 2012). In a study of 15,353 urban poor CKD patients in San Francisco, Hall and colleagues (2010) found that 8% of the patients were alcoholics and 16% had SUDs. Lemke and Schaefer discovered that nursing home residents with SUDs were more likely to have kidney failure (Lemke & Schaefer, 2010).

SUDs have a significantly negative impact on individuals with kidney disease. Importantly, persons with ESRD and SUDs may be significantly more likely to commit suicide than individuals who have ESRD and no SUDs (Kurella, Kimmel, Young, & Chertow, 2005). CKD and ESRD can impair the metabolism of opioids (Hardy, Herbert, & Reymond, 2007; Mercadante & Arcuri, 2004). In addition, a history of chronic opioid use before kidney transplantation may be significantly related to higher mortality risk after transplantation (Barrantes et al., 2013).

Interestingly, some studies suggest that moderate alcohol use may be inversely related to CKD risk, with individuals who consume some alcohol having less CKD (Cheungpasitporn et al., 2014; Dunkler et al., 2015; Hsu, Pai, Chang, Liu, & Hsu, 2013; Koning et al., 2015; Kusek, 2015; Presti, Carollo, & Caimi, 2007; Sato et al., 2014). However, a systematic review of studies related to the relationship between alcohol consumption and renal impairment concludes that this beneficial relationship has not been consistently demonstrated (Buja, Vinelli, Lion, Scafato, & Baldo, 2014). A high use of alcohol and alcoholism are actually related to increased risk for AKI (Camilleri, Wyatt, & Newstead, 2003), ESRD (Perneger, Whelton, Puddey, & Klag, 1999; Schaeffner & Ritz, 2012), and CKD (Hall et al., 2010; Jain & Reilly, 2014; Sato et al., 2014; Shankar, Klein, & Klein, 2006; van Gastel et al., 2015; White et al., 2009). In addition, Almaguer and colleagues (2014) report that consumption of homemade alcohol may be associated with CKD.

SUBSTANCE USE DISORDERS IN DIALYSIS POPULATIONS

As many as 19% of hemodialysis patients have been diagnosed with a current SUD (Cukor et al., 2007). In one study of hemodialysis patients, 27.6% of patients scored positively for alcoholism, and alcoholism was more prevalent in dialysis patients who are HIV-positive, younger, and male (Hegde, Veis, Seidman, Khan, & Moore, 2000). This study also found that alcoholic dialysis patients had lower albumin levels.

SUBSTANCE USE DISORDERS IN KIDNEY TRANSPLANT POPULATIONS

ESRD patients with a history of SUDs are significantly less likely to be on the waiting list for a kidney transplant, or to receive a kidney transplant if they are on the list (Sandhu et al., 2011).

Alcohol use may be negatively related to survival and kidney graft survival in transplant patients with alcohol dependency before or after the transplant (Gueye et al., 2007). After a transplant, an SUD may relate to poor immunosuppressant self-management and lead to graft loss (Dew et al., 2007; Parker, Armstrong, Corbett, Day, & Neuberger, 2013). Pain medications may cause nephrotoxicity in kidney transplant patients, which is exacerbated by immunosuppression regimes (Launay-Vacher, Karie, Fau, Izzedine, & Deray, 2005).

Substance use may be contributing to kidney transplant disparities (Hod & Goldfarb-Rumyantzev, 2014), including individuals who are HIV-positive (Sawinski et al., 2009). SUDs after kidney transplantation may contribute to poor transplant self-management (Bunzel & Laederach-Hofmann, 2000), and greater post-transplant mortality (Gill, Abichandani, Kausz, & Pereira, 2002). In Switzerland, one study concluded that alcohol use is less prevalent in adult kidney transplant patients than the general population and that none of their study patients were consuming alcohol excessively (Fierz et al., 2006).

There are SUD implications for kidney transplant donors as well. One study found that 4% of kidney donors had emotional, psychological, or SUD issues related to their donation, and 29% of donors had a history of psychiatric conditions or SUDs pre-donation (Jacobs et al., 2015). The kidney donors with at least one emotional, psychological, or SUD difficulty after donation were significantly more likely to feel unsupported by healthcare providers, feel that "no one paid attention" to their needs, and think that the kidney recipient did not show enough gratitude (Jacobs et al., 2015). Interestingly, there is evidence that transplants from kidney donors with a history of alcohol dependency or intravenous drug use are as successful as those from donors without such a history (Lin et al., 2005). However, methamphetamine use in kidney donors is associated with worse graft outcomes in kidney transplant recipients (Inouye, Kickertz, & Wong, 2007).

SUBSTANCE USE DISORDERS AND MENTAL HEALTH

There is a significant relationship between mental illness and SUDs, with 25.7% of individuals with a serious mental illness also having co-occurring SUDs or alcohol dependency (SAMHSA, 2012). Depression and alcohol use often frequently co-occur (Witkiewitz & Stauffer, 2014), and there is an association between high-risk alcohol consumption and anxiety as well (Knychala, Jorge, Muiz, Faria, & Jorge, 2015). Older adults with mental illness and SUDs may have greater risk for CKD (Lin, Zhang, Leung, & Clark, 2011). Substance use should be assessed along with depression, as SUD may be a comorbid condition with depression (Cohen, Norris, Acquaviva, Peterson, & Kimmel, 2007).

NEPHROLOGY SOCIAL WORK PRACTICE RECOMMENDATIONS

Nephrology social workers will greatly benefit from ongoing information and education regarding the treatment of patients with SUDs, given the significant individual and societal consequences. Many social workers are well trained to understand and deliver SUD care (Andrews, Darnell, McBride, & Gehlert, 2013), and are the primary service provider for such care (Wells, Kristman-Valente, Peavy, & Jackson, 2013). Nephrology social workers are usually the most qualified behavioral health experts in their practice settings, and should embrace leadership in this area.

As a foundation to working with such individuals, it is critically important to first be mindful of the language used to describe patients with SUDs (Chahine, 2013). In an editorial for the *American Journal of Public Health*, Wakeman (2013) strongly encourages all professionals working with these populations to be careful to use the term "substance use disorders" and never use the term "abuse." She suggests: "'Abuse' is arguably the most pernicious and poorly chosen word in our medical addiction vernacular. No other syndrome in medicine in its very naming explicitly labels the patient as the perpetrator of disease" (p. e1). Nephrology social workers can do in-service trainings for their interdisciplinary colleagues to support their understanding of terminology related to SUDs, and their overall understanding of the stigma individuals with SUDs may experience during treatment.

Because of the high prevalence of SUDs, all social workers need to be able to identify and assess SUDs and deliver relevant interventions (Galvani & Forrester, 2011) (see **Table 1**). As Lundgren and Krull (2014) suggest, given that the majority of individuals who have SUDs do not enter treatment, social workers play a key role in providing these services. *The National Association of Social Worker's Standards for Social Work Practice with Clients with Substance Use Disorders* (http://www.naswdc.org/practice/standards/Clients_with_Substance_Use_Disorders.asp) provide the following recommendations for social work practice related to SUDs (National Association of Social Workers (NASW), 2013):

- Social workers should understand the "psychological and emotional factors, physiological issues, diagnostic criteria, legal considerations, and co-occurrences of mental health disorders and substance use" (p. 11).
- Social workers need knowledge about current evidence-based practices for individuals with SUDs (this includes seeking specialized training).
- Social workers should assess clients for SUDs.
- Social workers need to evaluate their practices to determine effectiveness.

Table 1. Substance Use Disorders Practice Resources for Nephrology Social Workers

National Association of Social Worker's (NASW) Standards for Social Work Practice with Clients with Substance Use Disorders	http://www.naswdc.org/practice/standards/Clients_with_Substance_Use_Disorders.asp
Substance Abuse and Mental Health Services Administration (SAMHSA)—National Registry of Evidence-based Programs and Practices	http://www.samhsa.gov/nrepp
World Health Organization's (WHO) mhGAP Intervention Guide	http://www.who.int/mental_health/mhgap/en/
Screening, Brief Intervention and Referral to Treatment (SBIRT)	https://www.samhsa.gov/sbirt

- Social workers have to document services related to SUDs.
- "Social workers shall organize their workloads so as to fulfill their responsibilities and clarify their critical roles while providing services to clients with substance use disorders" (p.14).
- SUD social work practice needs to reflect cultural humility.
- Social workers should exhibit interdisciplinary team leadership and collaboration to help individuals with SUDs.
- Social workers need to advocate for individuals with SUDs.

SAMHSA has a *National Registry of Evidence-based Programs and Practices* (http://www.samhsa.gov/nrepp) that can be helpful for nephrology social workers to learn more about best practices for individuals with SUDs. Since nephrology social work provision focuses on kidney disease care and relevant needs, social workers in dialysis and kidney transplant settings likely do not have the time or resources to be the actual provider of a full spectrum of evidence-based practices needed by patients with SUDs. *The World Health Organization's (WHO) mhGAP Intervention Guide* offers some guidelines for health practitioners in non-SUD settings to help patients with SUDs (http://www.who.int/mental_health/mhgap/en/) (WHO, 2010). Such practitioners (which include nephrology social workers) need to be able to assess for SUDs and be knowledgeable about brief interventions and community resources for SUD services.

Medical settings, such as dialysis and transplant centers, can be promising locations for screenings and brief interventions for SUDs (WHO, 2014). One helpful tool that can assist nephrology social workers in screening and referring patients for SUD services is the Screening, Brief Intervention and Referral to Treatment (SBIRT) tool. SBIRT is evidence-based (Agerwala & McCance-Katz, 2012; Field & Holleran Steiker, 2012; Gryczynski et al., 2011) and shows promise in decreasing SUDs for individuals receiving care in medical settings (Bliss & Pecukonis, 2009; Woodruff, Eisenberg, McCabe, Clapp, & Hohman, 2013). SBIRT is used in health facilities (Straussner, 2012) and nephrology social workers are well suited to implement this tool (Cochran, Roll, Jackson, & Kennedy, 2014). SAMHSA has extensive resources and trainings for social workers in SBIRT on their website https://www.samhsa.gov/sbirt, including information for social workers about brief SUD screenings such as the Alcohol Use Disorders Identification Test (AUDIT) and theDrug Abuse Screen Test (DAST). Nephrology social workers can complete SBIRT training online. NKF-CNSW chapters could also have trainings on SBIRT for their members. Nephrology social workers can use these tools to screen patients for SUDs, and make referrals for treatment beyond their dialysis or transplant centers as indicated.

Nephrology social workers can also provide SUD patients with emotional support and encouragement to seek SUD services. In particular, dialysis and kidney transplant social workers can provide supportive counseling to patients who have CKD because of SUDs. These patients may be struggling with feelings of guilt or anger that their kidney failure was a result of SUDs. For example, the use of methylenedioxymethamphetamine (ecstasy) can lead to kidney failure (Campbell & Rosner, 2008; Howse & Bell, 2011; Pendergraft et al., 2014; Ricaurte & McCann, 2005). This can happen after only one dose of methylenedioxymethamphetamine (Campbell & Rosner, 2008). Patients in that situation likely will need social work support as they cope with their diagnosis and treatment regimen. Nephrology social workers can also provide patients' families with emotional support as they cope with their loved ones' SUD. Nephrology social workers in pediatric settings also need to be mindful of SUDs in their adolescent populations (Steele, Belostotsky, & Lau, 2012).

As SUDs in pre-transplant ESRD patients predict SUDs after kidney transplant (Dew et al., 2007), kidney transplant social workers need to include SUD assessment in their evaluation of patient suitability for transplants (or need to refer patients to team mental health professionals who are responsible for such screenings). In addition to assessing for current risk of SUDs, it is recommended that transplant social workers also explore patients' motivation to discontinue SUD behaviors and past attempts to quit the use of alcohol and drugs (Kuntz, Weinland, & Butt, 2015). In kidney transplant populations, hair toxicology testing of transplant recipients is recommended to detect alcohol and substance use, and is preferable to breath, blood, and urine tests (Haller et al., 2010).

Kidney transplant social workers can create some best practice guidelines for working with ESRD transplant candidates who have SUDs. These situations can lead to ethical challenges, as there are no common guidelines regarding the length of time a patient needs to be substance-free before being placed on a kidney transplant list. In addition, in states that now legalize marijuana, there are no common guidelines about kidney transplant candidacy and marijuana use.

Adolescent kidney transplant patients may require close follow-up by social workers. One small Belgian study of kidney transplant patients aged 10–18 reported alcohol use by 35% of the sample, and one of the respondents was using illegal drugs (Dobbels, Decorte, Roskams, & Damme-Lombaerts, 2010). Encouragingly, a qualitative study of adolescent kidney transplant patients in Australia suggests that these patients want information about alcohol and drug use (Tong, Morton, Howard, McTaggart, & Craig, 2011).

With the Affordable Care Act expanding Medicaid benefits for integrated health services that include SUD treatment (Andrews et al., 2015; Dey et al., 2016), nephrology social workers may find additional resources in their community to help patients with SUDs. Dialysis and kidney transplant social workers can work with their colleagues in local SUD treatment facilities to best provide services for kidney disease patients (and may bring these colleagues to local CNSW meetings for trainings). They can also advocate for expanded SUD services that work for kidney disease patients. This may be particularly necessary in rural areas that have SUD service gaps (Browne et al., 2015) or for inpatient services that will accommodate dialysis. Advocacy to enhance patients' insurance coverage for integrated kidney disease and SUD care is also needed across the country, as healthcare is reformed with our new administration, and the Affordable Care Act is potentially dismantled.

Nephrology social workers can work with their local communities to improve housing resources, as individuals experiencing homelessness are particularly at risk for poor CKD and ESRD outcomes when they have SUDs (Hall et al., 2012). Social workers employed by ESRD Networks across the country can improve available resources for nephrology teams and patients with SUDs. Dialysis social workers can also advocate for their patients receiving SUD care within their own clinic if patients need alternative or flexible dialysis scheduling to accommodate SUD appointments.

In order to best help CKD patients with SUDs, nephrology social workers may need to advocate within their own practice setting as well as at a policy level. If dialysis social workers are overwhelmed with high caseloads and inappropriate clerical tasks (Merighi & Browne, 2015), they will not have the time to provide clinical social work interventions needed to help patients with SUDs. Kidney transplant social workers need to advocate in their own clinics as well as at a policy level for support for post-transplant social work services. Nephrology social workers can find information and support for such professional advocacy by becoming a national member of the Council of Nephrology Social Work (https://www.kidney.org/professionals/CNSW), and joining the Council's email listserv, as well as attending the annual National Kidney Foundation Spring Clinical Meetings (https://www.kidney.org/spring-clinical). The NKF Spring Clinical Meetings have an entire track of continuing education sessions related to nephrology social work practice.

Substance use affects many people around the world, and can lead to severe health consequences, including death and disability. Overall, the intersection of SUDs and kidneys is complex, affecting all stages of kidney disease and all kidney disease populations. Nephrology social workers can play an important role in helping patients with SUDs, and work with their interdisciplinary teams to best help patients with SUDs.

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Chronic Kidney Disease Self-Management "Helps" and Hindrances in Older African-American and White Individuals Undergoing Hemodialysis:

A Brief Report

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This brief report summarizes chronic kidney disease self-management "helps and hindrances" among older African American and White individuals undergoing in-center hemodialysis. Qualitative data from 107 interviews were analyzed using steps of content analysis. Seven "helps" and five hindrances were revealed. The "helps" were: following treatment orders/adherence; a social network; exercise and physical activity; faith practices/beliefs; distractions during treatment; maintaining a positive attitude; and resting. The hindrances were: functional limitations; managing co-occurring conditions; diet and fluid restrictions; feeling fatigued on treatment days; and social network/social activities. The authors conclude with five practice recommendations for increasing self-management behaviors among individuals undergoing hemodialysis.

INTRODUCTION

Self-management, the active participation in one's care, is important for overall management of chronic kidney disease (CKD), the person with CKD being viewed as central to the interdisciplinary treatment team (Washington, Zimmerman, & Browne, 2016). Self-management is prioritized in the Conditions for Coverage because people undergoing hemodialysis are encouraged to participate in their own care (Alt & Schatell, 2009; Browne, 2012). The benefits of chronic disease self-management are well documented. Self-management improves health behaviors, self-efficacy and health status, results in fewer visits to emergency departments (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2000), lowers medical costs (Bodenheimer, Lorig, Hohman, & Grumback, 2002), and improves physical, emotional, and social functioning (Heisler, Smith, Hayward, Krein, & Kerr, 2003). Moreover, participants in self-management programs experience decreased pain, improved functional status, and increased quality of life (Kwog, Au, & Li-Tsang, 2016). These benefits warrant further investigation of improved self-management among individuals with CKD.

Self-management is particularly important to older adults who carry the burden of living with multiple chronic conditions. Over two-thirds of older adults live with two or more chronic conditions (Centers for Disease Control & Prevention (CDC), 2013), and older adults represent the fastest-growing segment of the CKD population (Washington, Hilliard, & McGill, 2003). Self-management is complicated for adults of all ages; for example, navigating complex medication regimens (Tanner, 2004). Thus, increasing self-management behaviors among older adults living with chronic conditions is a public health priority (CDC, 2013)

Given the growing emphasis on self-management, particularly for older adults, and its benefits documented in the literature, it is surprising that there have been few attempts to qualitatively investigate factors that facilitate and impede those behaviors among older adults with CKD and undergoing hemodialysis. The goal of the current study is to examine participants' perceptions about factors that help and hinder successful CKD self-management. The findings in this brief report are part of a larger mixed methods self-management study with 107 participants with CKD, aged 50 and older (Washington, Zimmerman, Browne, 2016). The theory guiding the larger study is social cognitive theory which describes the influence of personal and environmental factors that predict health behaviors (Bandura, 2001).

METHOD

In-person interviews consisting of closed and open-ended questions, were conducted with 107 individuals aged 50 and older, and undergoing in-center hemodialysis. This brief report summarizes responses to two open-ended questions: "What helps you manage well?"; and "What gets in the way of your ability to manage well?" This study was approved by the University of North Carolina at Chapel Hill Institutional Review Board.

Data Analysis

Because the surveys yielded a small amount of qualitative, yet informative, open-ended responses, steps of content analysis were used to open code the data, then inductively place those codes into respective categories (Hsieh & Shannon, 2005; Kondracki, Wellman, & Amundson, 2002). Following the open coding process, the categories were grouped into "helps" or "hindrances." The number of codes in each category were counted and reported accordingly; categories with four or fewer codes were grouped together into an "other" category.

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Table 1. Self-management "helps" and hindrances[a]

"Helps"	Count[b]
Following treatment orders/adherence	89
Social network	39
Exercise and physical activity	21
Faith practices/beliefs	18
Distractions during treatment	11
Maintaining a positive attitude	10
Resting	5
Other[c]	6
Hindrances	**Count[b]**
Functional limitations	16
Managing co-occurring chronic conditions	16
Diet/fluid restrictions	11
Feeling fatigued on treatment days	9
Social network/social activities	8
Other[d]	17

[a] Example quotes excluded for brevity

[b] Categories with 4 or fewer counts in "other" category

[c] Other = weight management, education, treatment options, access care, other activities

[d] Other = Emotional impact, loss of appetite, access care, limited transportation, limited travel opportunities, weight loss, time, death of others, caregiving

RESULTS

A total of 107 interviews were completed. Respondents were primarily African American (65%), and the mean age was 63. The number of men and women were nearly even (51% and 49%, respectively). Participants were undergoing in-center hemodialysis for an average of 7 years.

The content analysis revealed 7 "helps" and 5 hindrances to successful chronic kidney disease self-management (i.e., those receiving 5 or more counts). The "helps" were: following treatment orders/adherence (89), a social network (39), exercise and physical activity (21), faith practices/beliefs (18), distractions during treatment (11), maintaining a positive attitude (10), and resting (5). The hindrances were :functional limitations (16), managing co-occurring conditions (16), diet and fluid restrictions (11), feeling fatigued on treatment days (9), and social network/social activities (8). The categories and counts are listed in **Table 1**.

An overall definition of self-management was also identified. The following quote best represented the day-to-day tasks individuals with CKD must undertake to manage their condition while undergoing hemodialysis:

> *Well, other than taking my medications, coming to the dialysis center, and making my doctor appointments, I just do what I normally did before I started dialysis. Like if I have work to do around the home. You can't eat like a normal person and you can't plan like a normal person. Other than that, you're really living a normal life. I actually feel better than I have in the last two years and that means a lot to me.*

DISCUSSION

This brief report summarizes "helps" and hindrances of chronic kidney disease among older African American and White individuals undergoing hemodialysis. The qualitative data in this study were previously coded by four specific self-management tasks: cognitive symptom management, exercise, fluid adherence, and diet adherence (Washington, Zimmerman, Browne, 2016); this study extends those findings by pinpointing factors that facilitate and impede self-management. Regarding "helps," the interviews revealed that adherence to treatment orders and the presence of a social network aided in successful self-management.

About hindrances, respondents overwhelmingly described functional limitations and the management of other chronic conditions. This finding is not surprising given that over two-thirds of older adults live with more than one chronic disease (CDC, 2013). For instance, discomfort from co-occurring conditions were described as more painful than the effects of kidney disease, and oftentimes pain medications were used to obtain a tolerable level of comfort. Moreover, people complained about not being able to exercise and or do strenuous activities because of the pain and discomfort associated with co-occurring illnesses. These findings suggest co-occurring conditions negatively impact quality of life, even more than the discomfort associated with CKD. Thus, management of multiple chronic conditions is paramount if individuals with CKD are to achieve a desirable quality of life, and is also essential for decreased healthcare utilization and medical expenditures (Wolff, Starfield, & Anderson, 2002).

Interestingly, two categories overlapped as "helps" and hindrances. Nearly all participants recognized the importance of following treatment orders (e.g., attending all treatments, managing fluid intake, taking medications as prescribed, and eating proper foods); however, diet and fluid restrictions were seen as a hindrance to successful self-management. Also, the presence of a social network was identified as both a help and hindrance, especially when describing social activities such as managing food choices when visiting others, as evidenced by the following quote:

Table 2. **Comparison to Clark et al. study (1991)**

Self-management task in Clark study	Current study
Recognizing and responding to symptoms	
Using medicines	X
Managing acute emergencies	
Maintaining nutrition and diet	X
Maintaining adequate exercise/activity[a]	X
Giving up smoking	
Using relaxation and stress-reducing techniques[b]	X
Interacting with healthcare providers	X
Seeking information and using community services	
Adapting to work	
Managing relations with significant others[c]	X
Managing emotions and psychological responses to illness	X

[a] Reported in Washington, Zimmerman, & Browne (2016)

[b] Or cognitive distractions

[c] As identified by social networks in current study

> *This weekend, I probably ate and drank more than I should. When you're in someone's house, you don't want to tell them you can't eat or drink.*

When asked, "What helps you manage well?" many participants named individuals who helped them on a daily basis. Some named their spouses, others named their children and grandchildren, and others discussed social support associated with faith practices. This finding is consistent with previous self-management research with older adults who have other chronic conditions and who found family and friends to have both positive and negative influences (Gallant, Spitze, Prohaska, 2007).

Clark et al. (1991) were among the first to document common self-management tasks in older adults living with chronic conditions (i.e., heart disease, asthma, COPD, and diabetes). This research sought to connect self-management to psychosocial coping in older adults by explicating intrapersonal and interpersonal processes (Clark et al., 1991). For comparative purposes, the authors were interested in knowing how similarly the participants in this study described their self-management behaviors when compared to participants in the Clark study. The comparison is detailed in **Table 2**.

CONCLUSION

It is important to note that some people expressed no hindrances or concerns, as evidenced by the following two quotes:

> *I'm still doing the same things I was doing before. I eat good, watch what I eat, and watch my weight. I eat plenty of fruits, vegetables, and meats.*

> *Honestly, too much doesn't get in my way. When challenges come, you just deal with it and do what you have to do.*

Nephrology social workers may consider the overall findings in this brief report when employing self-management interventions. Opportunities exist to develop and implement interventions that help individuals with CKD their existing behaviors, and introduce them to new behaviors that have been successful with other chronic conditions. To aid in this consideration, the authors conclude with five practice recommendations and corresponding examples in **Table 3**. Nephrology social workers may consider implementing these strategies to increase self-management among individuals with CKD.

Table 3. **Five practice recommendations to increase CKD self-management**

Recommendation	Example(s)
1. Use technology for patient engagement	Send weekly text message reminders to patients; use group chat or video conferencing for patient support groups; regularly showcase exercise apps; start a patient social media page
2. Implement innovative activities	Allow patients to create self-management vision boards to hang throughout the facility
3. Distribute monthly pocket cards	Find ways to remember to take your binders; self-cannulation tips and techniques
4. Identify patient mentors	Hold annual elections for two or three patient mentors to serve as "self-management coaches"
5. Offer self-management incentives	Enter care plan attendee names into drawings for a small monetary gift card (e.g., $5 to a grocery store or "kidney-friendly" restaurant)

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Post-transplant Life:

Web-posted Stories of Parents of Children with Kidney Transplants

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Numerous studies have focused on understanding the well-being and life experiences of parents of children with varying special healthcare needs. However, only a few studies analyze the needs and issues of parents of children with chronic kidney disease (CKD) or a kidney transplant. This study explores the unique life experiences of these parents and identifies important factors that help families enhance their quality of life. Unlike previous studies, this investigation discovers that the majority of parents reported positive post-kidney-transplant outcomes along with positive perceptions of their children's special needs. This positive tone of web-posting stories is similar to previous research indicating that personal storytelling brings to light both resilience and therapeutic benefits. Thus, this study suggests that parental storytelling can be a useful psychosocial intervention that promotes the well-being of pediatric transplant recipients and their family members. Considering that more than half of parents in the study utilized the Internet to connect to other parents with similar experiences, professionals can encourage or incorporate forms of online interaction for parents to obtain information and support.

INTRODUCTION

A significant body of literature indicates that children with special healthcare needs or disabilities place substantial demands on parents/caregivers in terms of finances, employment, and mental and physical health (Gupta, 2007; Looman, O'Conner-Von, Ferski, & Hildenbrand, 2009; Shattuck & Parish, 2008). Among research on children with varying chronic illness, many studies specifically focus on families of children who underwent a solid organ transplant and examine the family's quality of life in terms of parental and sibling psychosocial adjustment and adaptation (Anthony, BarZiv, & Ng, 2010a; Anthony et al., 2010b; Sundaram, Landgraf, Neighbors, Cohn, & Alonso, 2007; Young et al., 2003). These studies reveal that a high level of stress is prevalent among families of children who received organ transplants. One study, measuring quality of life among pediatric kidney recipients and their parents, found that the emotional functioning of these families was negatively affected, regardless of their child's overall health and quality of life (Anthony et al., 2010b).

Although stress is often associated with raising a child with a disability or chronic illness, research employing qualitative (Green, Meaux, Huett, & Ainley, 2009; Tong, Lowe, Sainsbury & Craig, 2008; Tong, Lowe, Sainsbury, & Craig, 2010), quantitative (Glenn, Cunningham, Poole, Reeves, & Weindling, 2009), and mixed methods (Hall et al., 2012; Ylven, Bjorck-Akesson, & Granlund, 2006) has discovered that stress does not always lead to negative family outcomes. For instance, when describing difficulties in meeting their children's special healthcare needs, parents of children with pediatric heart transplants also expressed the blessings of having these children in their lives (Green et al., 2009). Parents can consider their children's disabilities or chronic illnesses as not only fulfilling a special purpose within their families, but also as enhancing family adjustment capabilities (Lassetter, Mandleco, & Roper, 2007; Trute, Benzies, Worthington, Reddon, & Moore, 2010) and their relationships with others (Ylven et al., 2006).

The Internet as a medium for socialization

The majority of today's parents use the Internet to find information and support regarding children, health, and family (Plantin & Daneback, 2009). Studies suggest that the Internet can be a medium of socialization for people with similar life experiences (Hamm et al., 2014). For example, the Internet has connected women with breast cancer (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005), parents of children with autism (Fleischmann, 2004; Fleischmann, 2005), and burn survivors (Badger, Royse, & Moore, 2011). Those studies also found that both online interactions and personal narratives are effective psychosocial interventions that may improve these populations' psychological well-being and coping skills. For instance, Fleischmann (2005) reveals that sharing personal experiences on the Internet allows stressed parents of children with autism to extract themselves from isolation and build relationships with others who have had similar experiences.

Benefits of storytelling

Previous studies demonstrate the therapeutic benefits of telling stories in terms of significantly improving physical and mental conditions, as well as coping skills (Carlick & Biley, 2004; East, Jackson, O'Brien, & Peters, 2010; Pennebaker, 2000). Sharing personal stories not only helps storytellers increase understanding of their personal experiences, especially traumatic events, but also helps form bonds and supportive networks (East et al., 2010). Sharing and listening to stories also enhance awareness of and reflection on life events and hardship. During the reflection process, studies

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found that both storytellers and listeners begin to establish meaning, develop greater self-awareness, and experience decreased emotional distress (Carlick & Biley, 2004; East et al., 2010; Hsieh, 2010).

Purpose of this study

Many studies have analyzed the needs and issues of parents of children with chronic kidney disease (Carolan, Smith, Hall, & Swallow, 2014; Tong et al., 2008; Tong et al., 2010), as well as parents of children who received kidney transplant (Anthony et al., 2010a; Anthony et al., 2010b; Brennan & McEnhill, 2011; Hsieh, 2010; Lerret et al., 2014). This study aims to expand the existing research on parents' and children's post-kidney-transplant experiences by: 1) exploring the unique life experiences of parents of children with a kidney transplant; 2) identifying important factors that help families enhance their quality of life; and 3) examining these parents' perceptions of their children's special needs to further understand the associations between the tone of their stories and the therapeutic aspects of storytelling. Rather than using researcher-guided interviews that explores caregivers' experiences, this study examines personal stories that were web-posted by parents of children with kidney transplants.

METHODOLOGY

Study design

This study used the Internet, via Google Search, to collect stories shared or posted by parents of children with kidney transplants. Two stages of data collection were conducted. In the first stage, five sets of key words were used to search relevant websites (e.g., "my child with kidney transplant, blog" and "blog, kidney transplant story, children"). To increase the study samples, this study employed a purposive sampling strategy, and also directly collected data from the Children's Organ Transplant Association's (COTA) website. COTA is a nonprofit organization that provides fundraising assistance for families of children who are undergoing transplantation. Many of those parents continue to update their children's and family's stories on the COTA's website after their child's transplant.

Data collection

Approximately 150 stories were retrieved from personal blogs or organization websites as a result of Internet searches between February and June 2013. This study had four screening criteria to select eligible stories: 1) the story was shared by the parent(s) or the guardian(s) of a child with a kidney transplant; 2) the length of story was 245 words or more; 3) the majority of the story was related to the child's post-kidney-transplant experiences; and 4) the family resided in the United States or Canada. As a result, 45 stories were found to be eligible for this study.

Analysis

This study utilized NVivo 10, a qualitative research software, to help the researcher analyze the content of the study samples. First, the researcher used the focused coding strategy (Bailey, 2007) to organize the data. The researcher wrote memos while coding and reflecting on the data. The researcher then analyzed the content by finding key words and counting the frequencies of relevant words and phrases. Lastly, the researcher identified themes by thoroughly examining the interactions and connections between the researcher's written memos and the results of the content analysis through NVivo 10.

Ethical concerns and protection of human subjects

The Institutional Review Board (IRB) of the University of Kentucky indicated that this study does not meet the federal definition of research (45 CFR 46.102(d)), thus, this study did not need an IRB review. According to Eysenbach and Till (2001), Internet content can be used for research purposes when the website and its content are considered to be publicly available information. This study' sample stories had the following features qualifying the content as publicly available information: 1) none of the sample stories had limited access that required registration to enter the website; 2) all the websites, including personal blogs or organizational websites, were designed to be viewed by the public at large, and many of them provided links and relevant services to others; and 3) the purpose of these personal blogs was to advocate for their children's special needs and to offer assistance to others in similar situations. To further protect people contributing materials, any information related to personal identities was deleted or de-identified.

STUDY RESULTS

Sample demographics

This study consists of a total of 45 web postings shared by parents of children with kidney transplants. These samples were collected from different types of websites, including personal blogs and foundation and hospital websites. Forty-two percent were collected from personal blogs (*n* = 19), 42.2% of the stories (*n* = 19) were located on foundation websites (e.g., The Atypical HUS Foundation, ARPKD/CHF Alliance) that provide health, social, and financial support for families dealing with kidney disease or other medical conditions, and 16.6% (*n* = 7) were from hospital websites (e.g., University of Maryland Medical Center, Boston Children's Hospital). Out of the samples collected from foundation websites (*n* = 19), 9 were directly retrieved from the COTA website.

The total 45 web postings represented 47 children who had received at least one kidney transplant at the time of data collection. Out of these children, 68% were male (*n* = 32) and 32% were female (*n* = 15). Two of these families had two children who had undergone transplantation. One of the families had a boy and girl of different ages, and the other family had a set of fraternal twins. Among these children, two had already received their second kidney transplant and the other three had both liver and kidney transplants in their lifetimes. For the majority of children, either their biological mother or father was the kidney donor (*n* = 28). There were two families in which neither parent was a good match for their child, so the parents participated in paired kidney exchange programs. While parents made up the majority of donors (60% ; *n* = 28), 17% were family members or family friends (*n* = 8), 17% were altruistic living donors (*n* = 8), and 6% were cadaver donors (*n* = 3).

THEMES

This study identifies three primary themes to demonstrate how these parents described their experiences regarding their children post-kidney-transplant, how they perceived their children's special health care needs, and what support they obtained to help them cope throughout their children's pre- and post-kidney-transplant journeys. These themes include positive outcomes with constant challenges, positive perceptions of the child's special health needs, and being embraced by support networks.

Positive outcomes with constant challenges

The majority of these parents (*n* = 44) shared positive post-transplant outcomes, including improved development and health of their children and their families' adjustments. Most of the children physically and mentally developed better and faster after the transplant. Many of the children started eating a variety of foods, instead of only consuming low-potassium or low-sodium foods. Many of the children became strong enough to sustain typical school hours. In one parent's words, "He had an amazing year at the 'Big Boy' school and finished first grade. He did better than we could have ever imagined. He only missed four days of school and he had one of the best attendance records." Another parent said, "A_____ is now running around and loving the independence. He is trying more things and we keep working on this [sic] eating skills daily. He is growing like a weed; we couldn't be more excited about his progress."

The posted stories described quality of family life as better after children received their kidney transplant. For instance, these families started trying things that their children's health did not allow them to do before transplantation. Some of the young children started attending daycare or preschool a few days a week, so that the primary caregiver, usually the mother, could have time to rest or complete educational or career goals. Without the need for and inconvenience of medical equipment (e.g., dialysis machines or feeding tubes), many of the families said that they had gone on several trips. Children with transplants could now have sleepovers, as well as participate in outdoor activities. The following story describes the family's gratitude for their new post-transplant lifestyle:

> [Thankful] for allowing him to have sleepovers, go to the beach and get in the water, for having a POOL birthday party and eat all the ice cream he wanted at it. For not being hooked up to a machine for 10 hours every night of his life, being afraid of infections constantly, for not being weighed and blood pressure checked every morning and night, for not being on more blood pressure medicine than his own grandfather, for and for and for—you get the picture. We could literally go on all day.

As many parents mentioned, "transplant is not a cure but a treatment." All parents acknowledged that their children might face organ rejection or might need another kidney later, even though they had experienced a more positive life after transplantation. Receiving a pediatric kidney transplant did not mean an end to their children's medical difficulties. Instead, they started experiencing different types of medical interventions and treatments. For instance, dialysis was replaced by numerous antirejection medicines and ongoing lab work. It was also common that these families faced varying bumps in the road when their children had kidney rejections or infections. Two of the children in this study already had their second kidney transplant due to rejection. After the first rejection, these two families underwent the agony of a second search for an organ donor match. During this process, these children were back on dialysis treatments. The following parents' story described one child who received a second kidney transplant.

> Over the last 7 years, E_____ has had over 40 surgeries, multiple infections and countless hospital stays. E_____ has a J-tube for feeds, because during his second attempt to redo a Nissen fundelplacation his stomach prorated, and he became very sick. E_____ has a mitrofanoff, which we catheterize him through his belly button to get his urine out. E_____ also has a M/ACE which use [sic] for bowel flushes. Oct[ober] 2009, our lives would change again. E_____ became very sick and was rejecting the kidney. He went into three types of rejection.

During the post-transplant stage, these parents not only continued to meet their children's medical needs, but also spent time and effort to improve their children's developmental and mental needs through education and rehabilitation. Many of these children have developmental delays as a result of their kidney failure, as well as other congenital or genetic disorders. Thus, they were in need of varying therapies, medical interventions, and special education to promote their development. The following story demonstrates how the parents of twins with kidney transplants address their children's disabilities on a daily basis.

> But realizing that as he is so heavy now and still unable to support his head and therefore most difficult to carry, that upstairs is not really an option, so we are trying to figure out where to settle F_____ in. I won't say they are small challenges, because they are not. In some ways dealing with their disabilities

> is more challenging than dealing with kidney stuff. Less terrifying but more upsetting. But, at the end of the day, although these issues can make us worried or sad, they are not life-or-death issues. The babies are healthy and for the most part happy! They have overcome tremendous obstacles and we stand amazed at where they are at. And we feel lots of hope!

Positive perceptions of the child's special health needs

Although some parents expressed negative feelings during their children's medical crises and during the complications, either before or after the kidney transplant, the majority of these parents ($n = 44$) described a positive outlook on having a child with special healthcare needs in their lives. These parents often perceived or described their child as a "true soldier," "a fighter," and their "hero," as well as being "strong." Most of these parents felt "blessed" and described how their lives were enhanced when they observed how strongly their children fought their diseases, and experienced the support of their family and friends. Although they understood that their lives were not going to be easy, they felt grateful and blessed that their children were with them. Parents with religious beliefs described these hardships as either temporary tests from God, or a special blessing to strengthen their life and faith. The following story shows how the parents found comfort and strength through their religious beliefs.

> He [child with transplant] continues to amaze and inspire us all with his passion for life and how hard he works. Every day he faces challenges with his disabilities and medical issues, but God has given him the gift of "Innocence," where he takes each day like it were typical. We are reminded every day what a "Miracle" he is and how much he struggled to be alive and healthy today.

On the other hand, less religious parents described how they had come to terms with reality and accepted their children's special needs. Parents sometimes claimed that their child made them better and stronger people, with a different perspective on life. The following story demonstrates this:

> All of the surgeries, hospital stays and visits, dialysis treatments, tests, therapy sessions, blood draws, the sleepless nights and all of the tears—we lived that. Not only did we live it, but we survived it, and I am so proud of who we have become because of the journey that we chose to live. It was a journey of struggle and heartache, but it was also a journey of determination and love for one little boy. A little boy who has taught us more in his three years of life than we have learned in our 28–30 years of life.

Embraced by support networks

According to these parents' posted stories, they all showed great appreciation of their family members, friends, or donors who had supported them throughout the transplantation journey. Many of them wrote about how they obtained information and emotional support from people with similar experiences through the websites of foundations and organizations, including personal support networks, social media (e.g., Facebook, Twitter), and personal blogs. Many parents described how they not only used the Internet to connect with similar people, but also to advocate for their children's special needs by getting involved in various activities (e.g., hosting fund raising events, sharing their stories publically, organizing support group). In addition to posting stories on personal blogs, two of the parents even began a social networking website for other parents of children with special needs who were inspired by their children's diseases. The following example shows how a parent had interacted with similar families before and after their child's transplant.

> The day after we learned about his PKD, I agreed to volunteer for the PKD Foundation and start their Atlanta Chapter. I'm thankful for the PKD Foundation and their staff for many reasons, but most of all, being a part of it has made me a better advocate for the kids. In addition, I've made friendships with other parents who share our challenges.
>
> I have found an amazing group of moms on Facebook, and they keep me sane. It's nice to have so many moms (and one dad) that know what we are going thru (sic) and can understand when I need to vent.

Discussion

Overall, the majority of parents reported positive post-kidney-transplant outcomes, including improvement of their children's medical conditions and development, and better quality of family life. The most striking change was that these families started trying things that their children's health did not allow them to do before the kidney transplant. These new changes in life included attending preschool or sustaining longer hours at school and learning activities, as well as having overnight family trips, sleepovers with other children, and various outdoor activities.

This study's findings have similarities and differences when compared to the previous studies (Anthony et al., 2010a; Anthony et al., 2010b; Young et al., 2003). Consistent with prior studies, these parents stated that the kidney transplant did not alleviate their responsibilities. They still had to meet their children's post-kidney-transplant needs, even years after the transplant surgery had occurred. For instance, parents stated that "transplant is not a cure but a treatment," as they still experience different types of medical interventions and treatments after the transplant. Unlike the previous studies that indicate the constant nature of the responsibilities and worries of parents of children with an organ transplant (Anthony et al., 2010a; Anthony et al., 2010b; Green et al., 2009; Lerret et al., 2014; Tong et al., 2010), the parents in this study often used a positive tone when describing their "tough" experiences meeting their children's medical and developmental needs. Many parents described in great detail how they had addressed post-transplant treatments and adjustments to their new lifestyles. Although they had been through various challenges, and sometimes had bad days throughout their children's pre- and post-transplant journeys, they viewed the process of coping with their children's special healthcare needs as an enriching experience. Many of them even perceived themselves becoming better, stronger people from raising their child. At the end of these parents' stories, most of them expressed optimism about their children's progress as they faced never-ending parental responsibilities, whether or not they disclosed having a religious belief.

Implications

In light of the findings, this study suggests several avenues for practical interventions as well as for future research in promoting better quality of life of parents and children with kidney transplants. Before deliberating the implications of the findings, several study limitations should be noted. First, even though this study established a set of sampling criteria, selection bias needs to be noted, especially when a personal blog published more than one story that met this study's sampling criteria. It should also be recognized that one single story can never fully represent the writer's holistic life experiences. For instance, this study found insufficient information about the extent to which parents utilized online support networks. The tone of the story could also be affected by the writer's emotional state at the time.

The complicated medical conditions of children with kidney disease or a kidney transplant make these children medically fragile, and this is the primary reason that these children and their family's social lives are limited. Formal and informal support seem to play essential roles in supporting these parents throughout their journey dealing with their children's kidney disease. For instance, many of the parents stated that the qualified and supportive care provided by their children's medical team helped to eliminate their stress and worries. In addition, this study reveals that these parents utilized the Internet to connect with people with similar experiences, as well as to advocate for their children's special needs. Considering social media technology is commonly employed for seeking information and support from others, this study suggests that interaction on the Internet could be an adaptive way to enhance practical connections with others for those who have restricted contact with the public due to their medical and health concerns. Also, as suggested by previous studies, the Internet has become a medium of socialization for people who have similar life experiences, including women with breast cancer, parents of children with autism, and burn survivors (Badger et al., 2011; Fleischmann, 2004; Fleischmann, 2005; Hoybye et al., 2005). Knowing the benefits of online interaction, health-related professionals and researchers have attempted to develop effective and integrated online interaction among people with chronic illness, traumatic experiences, or disabilities to engage in support groups or medical interventions (Carolan, Smith, Hall, & Swallow, 2014; Paterson, Brewer, & Stamler, 2013). Thus, this study suggests that professionals who are involved in assisting parents of children with a chronic disease or a kidney transplant should incorporate any forms of online interaction (e.g., origination, support group) for these parents to obtain information and support. Connecting these families to organizations and parent support groups not only increases their social opportunities with similar people, but also enlarges their support systems.

Healthcare professionals should note that there might be parents who have limited resources and access to the Internet. The study of Paterson and colleagues (2013) indicates that certain characteristics could affect the likelihood of people seeking information and support on the Internet, even though it is challenging to identify these people. Thus, this study suggests that healthcare professionals should consider issues with Internet access when referring patients and families to online support networks. Future research is needed to identify effective online intervention strategies, including characteristics of parents who are less likely to engage in online social support groups.

These web-posted stories demonstrate that these parents considered their children's disabilities or chronic illnesses not only as fulfilling a special purpose within their families, but as also enhancing family adjustment capabilities. This positive tone in describing their distress and hardship in meeting their children's medical and developmental needs is different from the past studies' findings regarding the quality of life of children with a kidney transplant and their parents and families. This positive outlook is similar to other studies' findings that indicate the advantages of personal storytelling (Badger et al., 2011; Carlick & Biley, 2004; East et al., 2010; Fleischmann, 2004; Fleischmann, 2005; Hoybye et al., 2005; Hsieh, 2010; Pennebaker, 2000). Storytelling can be an intervention strategy promoting the well-being of pediatric transplant recipients and their family members (e.g., parents and older siblings). Therefore, this study suggests that professionals should promote the benefits of oral and written storytelling, and encourage parents to share their feelings and experiences with online support groups and blogs as they cope with the stress of raising a child with special healthcare needs.

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National Kidney Foundation
2017 Spring Clinical Meetings Abstracts
April 18 – 22, 2017

CKD-ESRD – Other

1 **Incidence of Pain and Depression among Patients with End-Stage Renal Disease**
Kathryn Aebel-Groesch, Duane Dunn, Nancy Culkin, Angie Major, Sean Mayes, Deborah Benner.
DaVita Inc, Denver, CO, USA

2 **Putting Patients at the Center of Kidney Care Transitions: A Partnership Model for Kidney Disease Patients, Family Members and Community Stakeholders in Patient Centered Outcomes Research**
Prepare Now Workgroup: Teri Browne[1], Brian Bankes[2], Shakur Bolden[3], Kelli Collins[4], Patty Danielson[5], Gary Green[6], Katina Lang-Lindsey[7], Diane Littlewood[8], Jennifer Martin[4], Suzanne Ruff[9], Jennifer St. Clair Russell[10], Dori Schatell[11], Lana Schmidt[12], Dale Singer[13], Stephanie Stewart[14], Amy Swoboda[15], Brandy Vinson[16], Peter Woods[17], Jamie Green[8], Patti Ephraim[18], Tara Strigo[10], L. Ebony Boulware[10]. [1]University of South Carolina, Columbia, SC, USA; [2]Patient, Bloomsburg, PA, USA; [3]Patient, Jacksonville, FL, USA; [4]National Kidney Foundation, New York, NY, USA; [5]Adventist Health, Portland, OR, USA; [6]American Association of Kidney Patients, Tampa, FL, USA; [7]Patient, Montgomery, AL, USA; [8]Geisinger Health System, Danville, PA, USA; [9]Family Member, Mooresville, NC, USA; [10]Duke University School of Medicine, Durham, NC, USA; [11]Medical Education Institute, Inc., Madison, WI, USA; [12]Patient, Liberty, IL, USA; [13]Renal Physicians Association, Rockville, MD, USA; [14]Council of Nephrology Social Workers, NY, NY, USA; [15]Family Member, Edgewater, MD, USA; [16]Mid-Atlantic Renal Coalition, Richmond, VA, USA; [17]Patient, Hartsdale, NY, USA; [18]Johns Hopkins University, Baltimore, MD, USA

3 **Clinical Social Work End-of-Life (EOL) Survey**
Kevin A. Ceckowski[1], Dustin J. Little[1], Joseph R. Merighi[2], Teri Browne[3], Marie Salimbeni[1], Elizabeth I. Jones[4], Christina M. Yuan[1]. [1]Walter Reed National Military Medical Center, Bethesda, MD; [2]University of Minnesota-Twin Cities, St Paul, MN; [3]University of South Carolina, Columbia SC; [4]DaVita Sterling, Sterling, VA, USA

Transplantation

4 **Factors Affecting Interest in Transplant among End-Stage Renal Disease Patients Receiving Dialysis**
Deborah Evans,[1] Duane Dunn,[1] Rich Mutell,[2] Paul Broughton,[2] Deborah Benner[1]. [1]DaVita Inc, Denver, CO, USA; [2]Apex Health Innovations, Simi Valley, CA, USA

Other

5 **Shared Contracting in a Pediatric Dialysis Center**
Connie Perkins. Levine Children's Hospital, Charlotte, NC, USA

6 **The Thrills and Ills of Encouraging Employment Amongst ESRD Patients**
Wendy Tan, Wei Bin Chua, Job Loei, Srikanthan Rajagopalan, Crystal Goh. National Kidney Foundation, Singapore

1. INCIDENCE OF PAIN AND DEPRESSION AMONG PATIENTS WITH END-STAGE RENAL DISEASE: Kathryn Aebel-Groesch, Duane Dunn, Nancy Culkin, Angie Major, Sean Mayes, Deborah Benner; DaVita Inc, Denver, CO, USA

Chronic pain and depression can impact quality of life and adherence to treatment regimen among patients with end-stage renal disease (ESRD). Previous research has demonstrated that patients with ESRD experience pain and depression more frequently than the general population. From 2016, CMS has required that all eligible ESRD patients are evaluated regularly for pain and depressive symptoms.

We assessed pain and depression symptom scores among patients of a large dialysis organization (LDO) over the period Mar-Oct 2016. Pain is assessed monthly by LDO nurses using the Wong-Baker pain scale (0-10). Depression screenings are conducted biannually by LDO social workers using the PHQ-2 (scale 0-6) and exclude patients with existing diagnosis of depression or bipolar disorder, cognitive impairment or language barrier, and those who were hospitalized or refused screening.

A total of 688,346 pain responses from 160,626 individual patients and 223,421 depression screening responses from 158,172 patients were considered. A score of 0 (no pain) was reported for 83.5% of pain responses and 65.7% of patients had a 0 score in all pain assessments. A score of 10 (most severe pain) was reported at least once during the study period by 3.0% of patients. Patients with a pain score of 10 were more frequently female (55%) and patients on peritoneal dialysis were less likely to have a pain score of 10 than those on other modalities. A depression score of 0 (patient answered "Not at all" to both “Little interest or pleasure in doing things” and “Feeling down, depressed, or hopeless”) was reported for 69.1% of all responses and 62.6% of patients had a 0 score in all assessments; 1.8% of patients had at least one score of 6 (patient responded “Nearly every day” to both questions) and 9.7% had at least one score of 3 or more.

The majority of ESRD patients did not report pain symptoms and, among those not excluded from screening due to an existing diagnosis or other reason, the majority did not report symptoms of depression. However, routine assessment of pain and depression enables the timely identification of new or increased symptoms, thus allowing earlier implementation of interventions that may improve patient experience.

2. PUTTING PATIENTS AT THE CENTER OF KIDNEY CARE TRANSITIONS: A PARTNERSHIP MODEL FOR KIDNEY DISEASE PATIENTS, FAMILY MEMBERS AND COMMUNITY STAKEHOLDERS IN PATIENT CENTERED OUTCOMES RESEARCH: PREPARE NOW Workgroup, Durham, NC, USA

Patients, family members & community stakeholders are often peripherally engaged in patient centered outcomes research (PCOR). Our novel model includes patients & family members as Co-Investigators & community stakeholders as research partners in a currently funded clinical trial. Seven patients, 2 family members & 7 kidney stakeholder organizations partnered with researchers to develop an intervention, establish outcomes & write a proposal. We transcribed our meeting discussions, identified common themes, & refined our ideas prior to funding. Patients & family members were leading participants in all pre-award discussions & contributed to more than 5 major study design revisions.

Together, we created solutions to collaboration barriers (knowledge sharing, topic selection, time commitment, compensation). Patients & family members identified their most important research outcomes: control, empowerment, acceptance, grief, anxiety, depression & CKD knowledge. Patients & family members are Co-Investigators on this project, provide feedback on all components of the study protocol, revise all recruitment & communications materials, & ensure all aspects of the intervention respond to patient & family members' needs. Stakeholders are active participants in all of our project work groups, make recommendations related to project sustainability & dissemination, & along with the patient & family member Co-Is meet at least monthly with the team. Patients, family members & stakeholders can be fully engaged in research projects, thereby substantially improving the relevance & quality of PCOR studies. Our example could serve as a model to improve kidney disease PCOR studies & patient care.

3. CLINICAL SOCIAL WORK END-OF-LIFE (EOL) SURVEY

Kevin A. Ceckowski[1], Dustin J. Little[1], Joseph R. Merighi[2], Teri Browne[3], Marie Salimbeni[1], Elizabeth I. Jones[4], Christina M. Yuan[1]. [1]Walter Reed National Military Medical Center, Bethesda, MD; [2]University of Minnesota-Twin Cities, St Paul, MN; [3]University of South Carolina, Columbia SC; [4]DaVita Sterling, Sterling, VA, USA.

Clinical medical surgical social workers (CMSSW), mental health (CMHSW), and nephrology SW (CNSW) are critical to assisting nephrologists in conversations about Advance Directives (AD)/Medical Orders for Life-Sustaining Treatment (MOLST). We surveyed 221 clinical SW about EOL care, with a 49-item, anonymous on-line survey (Oct-Nov 2016). Response rate was 38%; 80% were CNSW, 13% CMSSW, and 7% CMHSW. Responses: 73% had caseloads >60 patients, averaging 15 deaths/year; 74% reported <25% of deaths were surprising/unanticipated; 68% reported ≤10% of patients were in hospice at the time of death; 45% reported ≤25% of patients had an AD/MOLST. Among SWs, 36% had a fully executed AD/MOLST; 52% had assisted a family member to complete an AD/MOLST. SWs with an AD were significantly more likely to have assisted a family member ($p<0.001$). In 51%, a life event had changed their opinion of EOL care. Only 42% stated that physicians discuss EOL care with patients, and 52% disagreed that physicians discuss AD with patients. The most frequent EOL referral barriers were physician discomfort discussing palliative care (63%) and hospice insurance (68%). About half agreed that they discuss hospice benefits with patients. In summary, SWs were comfortable having patient EOL discussions, but observe that many physicians do not discuss AD, and are uncomfortable discussing palliative care/hospice insurance issues.

The views expressed in this report are those of the authors, and do not reflect the official policy of the Department of the Army, the Department of the Navy, the Department of Defense, or the United States Government.

4. FACTORS AFFECTING INTEREST IN TRANSPLANT AMONG END-STAGE RENAL DISEASE PATIENTS RECEIVING DIALYSIS: Deborah Evans,[1] Duane Dunn,[1] Rich Mutell,[2] Paul Broughton,[2] Deborah Benner[1]; [1]DaVita Inc, Denver, CO, USA; [2]Apex Health Innovations, Simi Valley, CA, USA

For patients with end-stage renal disease (ESRD) receiving dialysis, receipt of a transplant offers the best possible long-term treatment option. The process of qualification for transplant involves many steps, beginning with the patient's statement of interest. We sought to characterize transplant interest among patients of a large dialysis organization (LDO) in the US and to explore reasons identified by patients for lack of interest in transplant.

Data on patient transplant status were derived from LDO electronic health records; this information is collected by LDO social workers during the course of routine care. Transplant status categories considered were: active, delisted, denied, in work-up, inactive, not interested, on hold, and pending patient follow-up. Reasons for lack of interest were assessed among patients not interested in transplant and characteristics of patients not interested in transplant were compared to those of patients with transplant status listed as active.

As of November 2016, there were 182,906 patients with available transplant status information in the LDO database. Of these, 58,057 (31.7%) expressed that they were not interested in transplant. Among patients not interested in transplant, the most frequently identified reasons for lack of interest were “advanced age” (25.7%), “perceived poor health” (12.0%), “comfortable with current modality” (12.0%), and “uninterested in further surgeries” (11.9%). Compared to patients with transplant status listed as active, those not interested in transplant were older (21.4% < 60 years vs 64.6%), more likely to be female (47.7% vs 36.6%); more likely to be white (43.9% vs 30.4%) and less likely to be Hispanic (14.7% vs 22.2%); more likely to be receiving in-center hemodialysis (92.0% vs 73.7%); and more likely to have Medicare as primary insurance (91.3% vs 77.3%).

Transplant education should respect the specific needs and choices of individual patients. Further research is needed to evaluate whether education and referral to a transplant center could provide patients with greater insight into transplant as an alternative to their current modality.

5. **SHARED CONTRACTING IN A PEDIATRIC DIALYSIS CENTER:** Connie Perkins, Levine Children's Hospital, Charlotte, NC, USA

Adherence to medical plans is crucial to optimizing successful outcomes for patients facing ESRD/dialysis. Formulating an *Understanding of Expectations* that includes patient/family input in developing the contract, outlining shared expectations, promotes buy-in and empowers the patient/family.

Patients/families identified by a healthcare professional as having difficulty adhering to their medications, treatments, appointments or meeting other behavioral expectations, were asked to meet with the medical team to share in problem solving the issue. Concerns and possible barriers to adherence were identified. Each participant clarified their expectations and responsibilities in helping the patient/family meet with success. The discussion resulted in a shared agreement of expectations.

Seven patients participated in the shared contracting from 1/2015 – 10/2016. The average patient age was 9.28±8.49 years. Of those, 71% of patients were on hemodialysis and 29% were on peritoneal dialysis. 71% of patients were female. The issues addressed included: treatment related (43%); fluids (29%); medication (14%); and appointments (14%). One month following the review and signing of the *Understanding of Expectations* contract, expectations were met in all areas with the exception of the adherence to dietary fluid allowance. Those improvements were inconsistent over the subsequent months. Expectations were reviewed during monthly care meetings and adjusted as needed.

Involving patients/families in developing *Understanding of Expectations* contracts and working as a team to address areas of concern enhances relationships and improves patient engagement. Including responsibilities for the healthcare team reduces the punitive perception of contracting and reinforces a team approach to healthcare. Continuous education, positive reinforcement and inclusiveness may positively impact patience adherence.

6. THE THRILLS AND ILLS OF ENCOURAGING EMPLOYMENT AMONGST ESRD PATIENTS: Wendy Tan, Wei Bin Chua, Job Loei, Srikanthan Rajagopalan, Crystal Goh, National Kidney Foundation, Singapore

In National Kidney Foundation Singapore (NKFS), we have over 4,000 needy patients receiving subsidised dialysis treatment. Regular dialysis and prolonged treatment impairs the physical and emotional state of End Stage Renal Disease (ESRD) patients. These patients opine that their current state of health limits their ability to perform certain job roles which are considerably physically demanding, such as being a driver, food & beverage/ retail assistant, construction/ engineering positions etc. Coupled with age and long-standing diabetic conditions, these factors further impede patients' functional status — i.e. level of clear vision, mobility independence, cognitive and alertness status, and heavy lifting ability. Formative research is conducted to explore and guide the aspects of motivation and resilience in ESRD patients. This research will gain insight into effective programme planning, develop better support systems for patients and how to optimise their rehabilitative outcome. It will also help in problem identification and solving through the provision of employment assistance. The research outcome will allow multi-disciplinary teams to better understand the patients' psychological well-being, suitable work conditions and employment needs for their patient clients. NKFS seeks to understand a patients' experience under this new initiative. Through this study, we would like to identify areas that patients were successfully supported and highlight the potential aspects that are important to further address. Through this formative study, NKFS also seeks to determine the sufficiency of the programme to meet patients' needs and capabilities. This qualitative study aims to document patients' experience of seeking and attaining employment. Through Interpretative Phenomenological Analysis (IPA), this study adopts semi-structured interviews to document patients' experience. Analysis is conducted after interviews to highlight patients' experience, areas that were successful as well as to identify areas for support enhancement. Formative research — 12 Focus group discussions with the target group comprises of patient employees of NKFS and patient job seekers. 6 In-depth interviews on attitudes, norms experiences, behavioural responses in seeking employment, and satisfaction reviews from the employers.

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