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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 nearly 1,000 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 Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The *JNSW* contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

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Clinical/Research Briefs. Abbreviated manuscript format presents clinical practice experience, preliminary research findings (basic or clinical), or professional observations in a shortened report form. Length should usually not exceed six double-spaced pages.

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.

Case Studies. These detailed scenarios should illustrate a patient care situation that benefited from clinical social work intervention. Typically, they should consist of a brief clinical and psychosocial history, and a detailed intervention plan with discussion of recommendations focused toward practical application.

Letters to the Editor. Letters should be restricted to scientific commentary about materials published in the *JNSW* or to topics of general interest to professionals working in the field of renal social work.

MANUSCRIPT SUBMISSION PROCESS

Important Update: JNSW now has an optional MS Word template available for preparing your article. Using it will enhance the production process. To obtain this template, send an email with "Template Needed" in the subject line to **jnsw@kidney.org**.

Note: A sixth edition of the APA style guide has been published. However, there were errors in the first printing which were corrected in subsequent printings. For now, *JNSW* will adhere to the fifth edition.

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Order of the Manuscript Sections

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2) Abstract
3) Text
4) References
5) Appendices
6) Author note
7) Footnotes
8) Tables
9) Figures
10) Figure captions

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All figure captions should be listed on a separate page, according to the order in which they appear in the manuscript. Multi-line captions should be double-spaced.

Reference Examples

Journal Article, Two Authors

Wassner, S. J., & Holliday, M. A. (1989). Protein metabolism in chronic renal failure. *Seminar in Nephrology, 9*, 19–23.

Journal Article, Three to Six Authors

Gartner, J., Larson, D. B., & Allen, G. D. (1991). Religion commitment and mental health: A review of the empirical literature. *Journal of Psychology and Theology, 19*, 6–25.

Journal Article, More Than Six Authors

Larson, D. B., Sherrill, K. A., Lyons, J. S., Craigie, F. C., Thielman, S. B., Greenwold, M. A., et al. (1992). Associations between dimensions of religious commitment and mental health reported in the *American Journal of Psychiatry* and *Archives of General Psychiatry*: 1978–1989. *American Journal of Psychiatry, 149*, 557–559.

Journal Article in Press

Odaka, M. (in press). Mortality in chronic dialysis patients in Japan. *American Journal of Kidney Diseases*.

Complete Book, Edited

Levine, D. Z. (Ed.). (1983). *Care of the renal patient*. Philadelphia: Saunders.

Chapter of an Edited Book

Nixon, H. H. (1966). Intestinal obstruction in the newborn. In C. Rob & R. Smith (Eds.), *Clinical surgery* (pp. 168–172). London: Butterworth.

Article from a Journal Supplement

Paganini, E. P., Latham, D., & Abdulhadi, M. (1989). Practical considerations of recombinant human erythropoietin therapy. *American Journal of Kidney Diseases*, *14*(Suppl. 1), 19–25.

Abstract

Bello, V. A. O., & Gitelman, H. J. (1990). High fluoride exposure in hemodialysis patients [Abstract]. *American Journal of Kidney Diseases, 15*, 320.

Editorial

Piantadosi, S. (1990). Hazards of small clinical trials [Editorial]. *Journal of Clinical Oncology, 8*, 1–3.

ACCEPTANCE PROCESS

If a manuscript is accepted for publication, the author will be required to send the following to the editorial office:

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The Festering Crisis of Inadequate Nephrology Social Work Staffing: What are the Options for Improvement?

William A. Wolfe, MSW
Women's Institute for Family Health of Philadelphia, Philadelphia, PA

Staffing has long been identified as a structural measure of quality in healthcare. In spite of this, it has not been accorded prominence in the CMS End-Stage Renal Disease (ESRD) program. Among the major consequences has been the absence of research on dialysis clinic staffing which could serve as a basis for developing evidence-based standards. In lieu of such standards, there has been a widespread arbitrariness in decision making about staffing, which has contributed to adverse patient outcomes and distress among the different disciplines trying to provide care. Largely ignored in these evolving developments has been the festering crisis in nephrology social work staffing, its ramifications for patients' psychosocial concerns not being addressed, and concomitant potential for the exacerbation of medical issues. This study provides a broad overview of these issues with social work staffing, and also suggests some pragmatic alternatives that could help mitigate the problem.

INTRODUCTION

Of all the subspecialties in medical care research, it has been demonstrated that social work intervention with end-stage renal disease (ESRD) patients has perhaps the greatest potential for impacting outcomes and costs. For example, depression is a widely prevalent problem among this patient population (Abdel-Kader, Unruh, & Weisbord, 2009; Battistella, 2012), and has been found to be associated with an increased risk for hospitalization and premature death (Lopes et al., 2004). Studies have established that therapeutic interventions by nephrology social workers can reduce the severity of depression (Johnstone, 2007), thus potentially mitigating complications and the associated costs. A second major problem common in ESRD patients is the struggle to limit fluid intake, as measured by excessive weight gains between treatments (Pace, 2007). Nonadherence to fluid restrictions can cause serious medical complications, including congestive heart failure (CHF) (Shotan, Dacca, Shocat, Kazatsker, Blondheim, & Meisel, 2005), exacerbation of hypertension (Rahman, Fu, Sehgal, & Smith, 2000), acute pulmonary edema (Abuelo, 1998), and earlier death (Kalantar-Zadeh et al., 2009). Research has similarly demonstrated that when nephrology social workers have adequate time for interventions they can help patients to better adhere to their fluid restrictions (Johnstone & Halshaw, 2003), thus lessening the chances of these complications. Missed and shortened treatments are a third common problem (Gordon, Leon, & Sehgal, 2003; Obialo et al., 2008) that studies have shown to result in increased morbidity and mortality risks (Obialo, Hunt, Bashir, & Zager, 2012; Saran et al., 2003). Again, investigations have demonstrated that when social workers have adequate time for therapeutic involvement, they can help decrease missed and shortened treatments (Cabness, Miller, & Martina, 2007), thus lessening the associated medical risks. Noteworthy has been Johnstone's leadership in introducing tools social workers can use to ease patients' initial adjustment to treatment (*Renal Business Today,* 2013). Finally, psycho-educational intervention by social workers has been shown to enhance medication adherence and improve chronic conditions such as blood pressure control (Beder, Mason, Johnstone, Callahan, & LeSage, 2003).

In spite of this demonstrated ability of social workers to positively influence patient outcomes through interventions, there remains a host of psychosocial problems impacting this patient population (Bakir & Dunea, 2001; Fink & Henrich, 2001; Foster, 2008; Hegde, Vels, Seidman, Khan, & Moore, 2000; Kimmel & Peterson, 2008; Santos & Arcanjo, 2013; Watnick, Kirin, Mahnensmith, & Concato, 2003; Wellington, 2000) which are inadequately addressed. Notwithstanding unknowns about the full extent to which these problems might be contributing indirectly to an exacerbation of morbidity and mortality risks, there is overwhelming evidence that social workers lack sufficient time for mandated involvement with patients (Bogatz, Colasanto, & Sweeney, 2005; Callahan, Witten, & Johnstone, 1997; Merighi & Collins, 2011; Merighi & Ehlebracht, 2002; Merighi & Ehlebracht, 2004; King, 2003). This has constituted a "hidden crisis" which, by definition, has been largely ignored in the literature. The purpose of this study is to provide an encapsulated overview of inadequate staffing. Within the sequence that follows, there is first a review of evidence supporting a crisis in nephrology social work staffing. Next, because the problems related to staffing with social workers are not an isolated phenomena, a brief foray is made into the broader context of staffing as a longstanding neglected issue in the Medicare ESRD program. Finally, options for facilitating improvements in nephrology social work staffing are discussed.

EVIDENCE OF A CRISIS IN NEPHROLOGY SOCIAL WORK STAFFING

The architects of the ESRD program had the wisdom and foresight to recognize that patients would have many psychosocial needs adjusting to the disease and its treat-

Direct correspondence to: William A. Wolfe, MSW, 422 West Chelten Avenue, Philadelphia, PA 19144; 832.528.3404; **wol2will@aol.com**

ment, thus the mandated requirement for social workers (Department of Health, Education, & Welfare (HEW), 1976). With similar foresight, in 1983 the National Kidney Foundation Council of Nephrology Social Workers (NKF-CNSW) set forth recommended guidelines for staffing which called for one full-time social worker for every 75 patients (NKF-CNSW, 1987). Unfortunately, this recommendation has had little influence in limiting the actual patient workloads for which these professionals have had responsibility.

Tracing the crisis in staffing, evidence reveals it has been an evolving phenomenon over the 40 years of the ESRD program. Among the earliest observations was an Institute of Medicine study, *Kidney Failure and the Federal Government* (Rettig & Levinsky, 1991), which noted that the staffing of social workers decreased during the 1980s, rendering these professionals to those who perform “minimal routine functions rather than essential counseling considered optimal for patient care.” Overlapping with these observations made during the 1980s, the NKF-CNSW Executive Committee conducted a two-part survey, between June 1983 and June 1988, which was prompted by concerns regarding the quality of social work services provided in dialysis facilities (NKF-CNSW Executive Committee, 1989). Among the major findings of the survey was that many patients did not have access to a social worker. This inaccessibility was found to be due to social workers’ reduced hours, and having to travel between multiple clinics (which could sometimes be 50 miles apart). Evidence also surfaced during this period that excessive caseloads were contributing to the limited time social workers had available for patients. Davenport, Itschaki and Siegal (1993) reported, for example, that the mean caseload was 120 to 152 patients, with a high of 400 per single worker. In a second survey by the NKF-CNSW in 1994, conducted in conjunction with the American Association of Kidney Patients (AAKP), 40 percent of patients reported that they did not have access to a social worker when they needed one (Siegal, Witten, & Lundin, 1994). In 1997, Callahan, Witten, and Johnstone summarized key facts known about the evolving crisis in staffing to that date, which included: major increases in patient caseloads over the preceding ten years, and an emerging widespread practice among dialysis providers of imposing nonclinical tasks on social workers, which was undermining their ability to provide mandated clinical services. Reinforcing this evidence, Merighi and Ehlebracht (2002) reported on a survey, conducted by the Northern California CNSW Chapter, which found that social workers were spending, on average, a combined 13 hours weekly on clerical and insurance-related tasks, and only 10 hours counseling patients. Also in 2002, the New York Metropolitan CNSW Chapter published the results of its survey, which looked at the discrepancy between the roles of social workers and tasks expected of them (Russo, 2002). The survey revealed that instead of engaging in the patient-oriented tasks that their professional education prepared them to perform, a large number of social workers were doing “menial tasks” (e.g., arranging transportation, acting as a “bill collector” with patients), which were mainly imposed as cost-saving measures. Echoing the inaccessibility problems identified in earlier surveys of the 1980s and 90s, the National Kidney Foundation conducted a study in 2003 finding that 17 percent of patients “almost never” saw their social worker (King, 2003). Continuing with the evidence on the distractive burden of nonclinical tasks, Merighi and Ehlebracht (2004) reported on a national survey of dialysis social workers discovering that full-time workers spend approximately 17% of their time each week on insurance-related tasks, 15% on clerical tasks, 15% on patient charting, and only 15% counseling patients. Replicating the ever-growing evidence in this area, Bogatz, Colasanto, and Sweeney (2005) published the results of a survey, conducted by the Connecticut CNSW Chapter, which dramatically highlighted the struggles social workers were having. Among the findings were that 52.1 percent of social workers did not have time for psychosocial evaluations of patients; 73 percent indicated there was insufficient time for counseling; and 72.2 percent said there was not enough time for patient education. It is pertinent to note that a 2005 report found an association between these nonclinical tasks and emotional exhaustion among social workers (Merighi & Ehlebracht, 2005). The most recent evidence of the continuing crisis in staffing was a 2011 analysis examining the challenges confronting social workers since the implementation of the newest Centers for Medicare and Medicaid (CMS) Conditions for Coverage (CfCs) for ESRD facilities in 2008 (Merighi & Collins, 2011). Reinforcing the evidence accumulated over the years, investigators concluded that unrealistic patient workloads and nonclinical tasks, combined with the additional documentation requirements of the 2008 CfCs, were severely stifling social workers’ ability to meet their CMS-mandated responsibilities with patients.

While there appears to be overwhelming evidence of a crisis related to social workers’ inability to provide timely interventions, not known are its implications for exacerbating patient suffering, undermining the achievement of optimal outcomes and increasing costs. For example, while it has been demonstrated that social work interventions can help mitigate symptoms of depression (Johnstone, 2007), the medical and financial ramifications of these professionals not being able to provide sufficient therapeutic interventions are yet to be determined through research. The depths of the unaddressed needs in this area are suggested in statistics showing that only 16 percent of patients initiating dialysis are receiving help with their depression (Watnick, Kirwin, Mahnensmith, & Concato, 2003). Given that social workers can also help enhance adherence to fluid restrictions (Johnstone & Halshaw, 2003), not known are the consequences of not being able to provide more interventions to prevent increasing hospitalizations due to exacerbations of hypertension and congestive heart failure (CHF). These consequences could be quite significant given data showing that 70 to 80 percent of patients are not able to adhere to their fluid restrictions (White, 2004).

THE BROADER SCOPE OF STAFFING AS A NEGLECTED ISSUE IN THE ESRD PROGRAM

It is important to emphasize that the problems and unknowns related to nephrology social worker staffing are not isolated phenomena, but appear to be symptomatic of much broader problems in the ERSD program related to the subject of staffing (Wolfe, 2011). Most of the broader problems can probably trace their origins to the combination of a lack of priority given to staffing by CMS, and ambiguities in the regulations set forth in the CfCs for ESRD facilities on the subject. Both the initial CfCs issued in 1976 (HEW, 1976) and the newest regulations in 2008 (CMS, 2008) describe proper dialysis staffing occurring when:

> An adequate number of qualified personnel are present whenever patients are undergoing dialysis, so that the patient/staff ratio is appropriate to the level of dialysis care given and meets the needs of patients.

The fundamental problem with this regulatory statement would seem to be the vague phrase "adequate number of qualified personnel," which has remained undefined throughout the 40 years of the ESRD program. Given this area's total absence of regulation in most states (Wolfe, 2011), dialysis providers have had virtually unchallenged discretion in defining adequacy. The arbitrariness of decision making that has taken place over the years probably accounts for widely-fluctuating staffing ratios. For example, some nephrology social workers have 110 patients, and others have as many as 425 (Merighi, Browne, & Bruder, 2010). Within the Donabedian (1966) classic "structure, process, and outcome" model of measuring quality in healthcare, such wildly divergent staffing patterns would inescapably affect patient outcomes.

Evidence of the broader scope of problems and questions related to staffing can probably be best illustrated by looking briefly at the challenges other disciplines have also faced. Beginning with nephrologists, most of the controversy related to their staffing in clinics has focused on unknowns about the needed frequency of their contacts with patients during dialysis treatments, and whether it has any measurable impact on outcomes. Relative to the frequency question, CMS changed its reimbursement policy in 2004 to incentivize more visits, with the assumption that more frequent contacts would improve outcomes (DHHS, 2003). Research on whether this has had the desired effects has been mixed, and at times contradictory. For example, a group of investigators (Mentari, DeOreo, O'Connor, Love, & Sehgal, 2005) were the first to examine the changes in nephrologist visits since the changes in reimbursement policy and found an abrupt increase in per-patient monthly visits (from 1.52 to 3.14). Despite this dramatic increase in visits, they were not found to have any clinically important impact on quality indicators. In a second study (Plantinga et al., 2005), more frequent patient-physician contacts were found to be associated with achievement of performance targets for albumin, calcium-phosphate, and dialysis dose. Paradoxically, this same investigation discovered that patients receiving the highest frequency of visits were significantly less likely to be on a transplant waiting list. In a recently published report (Slinin et al., 2012), greater nephrologist-patient contacts were found to be associated with a small, but statistically significant reduction in the risk of first hospitalization. However, no consistent association was found between frequency of visits and patient risk of death. Along these same lines, a just-published 2014 study has suggested that one additional monthly clinic visit by nephrologists with patients just discharged from the hospital could significantly reduce readmissions (Erickson, Winkelmayer, Cherton, & Bhattacharya, 2014). Reflecting the continuing state of confusion about an evidence basis for nephrologist staffing, the latest investigation (Erickson, Tan, Winkelmayer, Chertow, & Bhattacharya, 2013) found that the frequency of visits depends more on geography and facility location, rather than the optimal management of patients. Finally, the pressing need for more research in this area was given additional impetus by the finding of a correlation between nephrologist caseload and patient survival, with higher caseloads being associated with poorer survival (Harley et al., 2013).

Turning to nephrology nurses, several examples can be found where the arbitrariness in decision making regarding staffing has had ramifications for both patients and nurses. Starting with patients, research has found that inadequate nurse staffing increases their risk for exposure to hepatitis C virus infections (Saxena & Panhortra, 2004), which has been linked to nurses' inability to consistently adhere to hand hygiene standards (Arenas et al., 2005; Shimokura, Weber, Miller, Wurtzel, & Alter, 2006). As to the ramifications for nurses themselves, there is overwhelming evidence linking the lack of adequate staffing to occupational burnout (Ashker, Penprase, & Salman, 2012; Flynn, Thomas-Hawkins, & Clark, 2009) and turnover rates as high as 150 percent (Gardner, Thomas-Hawkins, Fogg, & Latham, 2007). A recent analysis has even suggested that negative word-of-mouth communications from nurses who have disappointing work experiences in clinics might be dissuading others from considering the field of nephrology nursing, thus uniquely contributing to the shortage of these specialists (Wolfe, in press).

Focusing finally on renal dietitians, arbitrariness in decision making about staffing has been found to be associated with their inability to implement all 21 Adult Nutrition Guidelines (Burrowes, Russell, & Rocco, 2005; Vergil & Wolf, 2009), which are part of the NKF Kidney Disease Outcomes Quality Initiative (KDOQI) Clinical Practice Guidelines for Nutrition (National Kidney Foundation, 2000). Similarly, the reduced time renal dietitians have available for patients, also from inadequate staffing, has been found to be associated with their inability to provide intensive nutritional counseling (Wolfe, 2012).

OPTIONS FOR FACILITATING IMPROVEMENTS IN NEPHROLOGY SOCIAL WORK STAFFING

Surveys of nephrology social workers have revealed an increasing exasperation with unrealistic work demands and acknowledgement that many of the needs of patients are simply not being met. These service delivery difficulties are epitomized in the following observation from a respondent in an investigation by Bogatz, Colesanto, and Sweeney (2005):

> With such large caseloads it is impossible to meet the very complex needs of our primarily inner-city population. The combination of a more complex caseload and greater number of patients to cover make it impossible to adhere to the Federal guidelines as written. I believe our patients are being denied access to quality social work services.

Despite compelling testimonies like this from several reports, pragmatic directions for collective action by social workers which could begin a process to mitigate the crisis in staffing have not been forthcoming. The directions for such action suggested here are dictated by what is viewed as the three major contributing factors in the development and perpetuation of the crisis: the lack of priority given to staffing as a quality of care issue at the Federal level; investor-owned large dialysis organizations (LDOs) and labor cost containment; and insufficient political initiatives by nephrology social workers to influence policies and regulations.

THE LACK OF PRIORITY GIVEN TO STAFFING AS A QUALITY OF CARE ISSUE AT THE FEDERAL LEVEL

Because it pays the bills through reimbursement for services, CMS has dictated the rules, through the CfC, for the ESRD program since its creation in 1973. While this has been described as one of the most highly regulated programs administered by the Federal government (Rettig & Levinsky, 1991), there has been a perplexing absence of more specific rules about staffing in dialysis clinics. One major ramification of this has been that other entities (e.g., the ESRD Network Organizations, dialysis providers, and investigators) have tended not to view staffing as a quality of care issue. Instead, there has been a preoccupation with such indicators as adequacy of dialysis, anemia management, and the type of access patients are using. A secondary consequence has been the paucity of research on staffing, which could serve as a basis for developing evidence-based standards.

Given this lack of attention, one pragmatic step that could ultimately help to mitigate the crisis in social work staffing (and in other nephrology disciplines) is investigations which can begin to better inform policymakers about the clinical and financial ramifications of inadequate staffing. Because time is a critical variable with any professional in being able to carry out tasks (Dolecek et al., 1995), research is needed on the variety of responsibilities performed by social workers. For example, given the high prevalence of depression among this patient population (Abdel-Kader et al., 2009), what are the time requirements for social workers to provide needed psychotherapeutic interventions? If an association is found between decreased depression symptoms and a lower risk of hospitalization, it will add an additional impetus for evidence-based staffing, in areas justified through cost savings. A second area where it is beneficial to have a better understanding of the time needed for social work interventions is with the ever-growing elderly ESRD population (Rosner, Abdel-Rahman, & Williams, 2010). It is known that these patients typically require more professional involvement because of their physical dependencies and comorbidities, including cognitive impairment (Sehgal, Grey, DeOreo, & Whitehouse, 1997). Among the areas where a better understanding of the specific social worker time requirements would be helpful is providing and facilitating various types of social support. It is known that ESRD patients often experience loss of support because of their disease (Browne, 2006). Having adequate time for such interventions is important because research demonstrates an association between enhanced support, improved quality of life, fewer hospitalizations (Plantinga et al., 2010), and better patient survival (Thong, Kaptein, Kredict, Boeschoten, & Dekker, 2007). A third and final area where studies are clearly needed is the requisite time for social workers to carry out required functions in clinics serving the urban poor. It is known that patients in these facilities have a higher social acuity, in terms of the multiple social and economic challenges they face daily (Bakir & Dunea, 2001; Fink & Henrich, 2001; Hegde, Vels, Seidman, Khan, & Moore, 2000; Kimmel, Fwu, & Eggers, 2013; Patzer et al., 2012). Illustrative of this, socio-demographic factors have been found to contribute to depression in African-American ESRD patients (Fischer et al., 2010). Reflecting the need for more adequate social work staffing, a recent investigation (Tapolyia et al., 2010) discovered that a “striking” 85.9 percent of African-American patients in the Southern region of the United States shortened at least one treatment, and 29 percent missed at least one session per month. Perhaps not surprisingly, these minority patients have a significantly higher risk of mortality than their white counterparts at ages 18 to 30 (27.6% vs. 14.2%), 31 to 40 (37.4% vs. 26.8%), and 41 to 50 (44.8% vs. 38.0%) (Kucirka et al., 2011). While the NKF-CNSW-recommended ratio of one social worker for every 75 patients might be appropriate for most facilities (1987), research may determine that given the elevated social acuity of urban units, a 1:50 ratio may be required for these professionals to carry out their mandated responsibilities.

INVESTOR-OWNED LARGE DIALYSIS ORGANIZATIONS (LDOs) AND LABOR COST CONTAINMENT

The absence of evidence-based staffing standards has given large dialysis organizations (LDOs) virtual carte blanche in determining staffing levels, and constitutes the second major factor contributing to the crisis in staffing. Labor cost containment has been an ongoing major objective of LDOs because staffing constitutes 50 to 70 percent of the expense of doing business (Ford & Kaserman, 2000; Grieco & McDevitt, 2012). This began in the 1970s with the widespread substitution of registered nurses with unlicensed patient care technicians (PCTs) (Hoffart & Nissenson, 1998; Meyer & Kassirer, 2002). The drive has continued through what has been called "staffing efficiencies" with all the disciplines (Sullivan, 2009), including nephrologists, nurses, dialysis technicians, dietitians, and social workers. Operating with an economy of scale orientation (Himmelfarb, Berns, Szczech, & Wesson, 2007), the continuous increases in the number of patients for which individual professionals have responsibility has helped to incrementally improve profit margins. It has simultaneously however, put extraordinary pressures on renal professionals. As Blades (2010) observed in *Social Work in Healthcare Settings: Practice in Context*, "Social workers are often squeezed in efforts to enhance profits." Given these economic dynamics, there would appear to be a good chance for further escalations of patient workloads because, as has been noted, the investor community is not satisfied with simply achieving a profitable plateau, but expect continual improvements in financial results (Hall & Conover, 2006).

Capitalizing on this profit motive, there are several areas where a business case can potentially be made for improved social work staffing. First, patient rehabilitation has long been an unfulfilled objective of the ESRD program (Kutner, Bowles, Zhang, Huang, & Pastan, 2008). The business case in this area comes from two interrelated facts. First, research (Callahan, Moncrief, Wittman, & Maceda, 1998) has demonstrated that the caseloads of social workers affect their ability to rehabilitate patients. Secondly, LDOs would appear to have a financial vested interest in more adequate staffing of these professionals because, when they are successful in supporting patients' ability to work, employer-group health insurances reimburse providers $180,000 annually (Just, de Charro, Tschosik, Noe, Bhattacharya, & Riella, 2008), compared to the $66,000 received for non-working patients.

Yet another area where LDOs would appear to have a vested interest in more adequate social work staffing is with the new pay-for-performance initiative by CMS called the ESRD Quality Incentive Program (QIP) (DHHS, 2012). This program imposes payment reductions on providers failing to maintain quality from year to year. Based on CMS estimates, the 2014 QIP could take close to $50 million directly out of the ESRD program, due to the number of facilities failing to meet their goals (Bhat & Bhat, 2012). Broken down into individual facilities, this could add up to $52,000 in financial penalties per clinic (Fishbane, Miller, Danko, & Masani, 2012). Among the quality indicators for which payment reductions will be made is a failure to maintain adequacy of dialysis, as measured in the urea reduction ratio "greater than 65%." Given the critical element of time in dialysis adequacy (Daugirdas, 2012; Lacson & Brunelli, 2011) and the fact that missed and shortened treatments greatly undermine its achievement (Sehgal et al., 1998), a business case for more sufficient social work staffing can be made because these professionals have demonstrated they can help reduce missed and shortened treatments (Cabness, Miller, & Martina, 2007), thus potentially helping to minimize payment reductions.

INSUFFICIENT POLITICAL INITIATIVES BY NEPHROLOGY SOCIAL WORKERS TO INFLUENCE POLICIES AND REGULATIONS

Healthcare policy encompasses decisions that determine rules and standards under which services for patients are organized, produced, delivered and reimbursed (Greipp, 2002). Because healthcare professionals have a direct day-to-day relationship with patients, political advocacy for select policies can be a powerful tool for advancing the best interests of patients (Priest, 2012). Demonstrating what can be accomplished, through a combination of political advocacy and marshalling evidence on the adverse effects of inadequate staffing, California nurses have been successful in getting the first comprehensive legislation passed in the United States to establish minimum staffing levels (Mark, Harless, Spetz, Reiter, & Pink, 2013).

The National Kidney Foundation Council of Nephrology Social Workers (NKF-CNSW) is the leading professional organization for social workers in this field. Despite a history of advocating for clinical standards, and having offered the highest number of public comments during the 2008 CfC changes, CNSW was informed that CMS would not address the staffing issue (L. Peace, personal communication, April 12, 2013). This refusal would appear to be indicative of the long-standing aversion to the subject of staffing by CMS emphasized throughout this study. Given the continuing centrality of inadequate staffing in so many issues confronting nephrology social workers (Bogatz et al., 2005; Callahan et al., 1997; Merighi & Collins, 2011; Merighi & Ehlebracht, 2002; Merighi & Ehlebracht, 2004; Merighi & Ehlebracht, 2005; Siegal et al., 1994; Wolfe, 2011), perhaps it is time for more assertive political advocacy for regulations. Adding impetus to this need for action are the unrelenting profit pressures on investor-owned LDOs (Hall & Conover, 2006), and the strong possibility that social workers will be squeezed even further to enhance profit margins (Blades, 2010).

NKF-CNSW would appear to be in a good position to spearhead such an effort because of its 800 members and 42 local Chapters, strategically situated across the United States. Utilizing their relationship skills as social workers, Chapter members could gradually begin to reach out to elected officials and policy makers, at both the state and Federal levels of government. Initiatives in each state are particularly important because it is at a level of government which has the jurisdiction to regulate patient workloads, as happened in the state of Texas. (State of Texas. Department of State Health Services Regulatory Licensing Unit Facility

Licensing Group, 2010). Such action by nephrology social workers would be consistent with the National Association of Social Workers' (2008) *Code of Ethics*, which mandates that these professionals should be aware of the impact of politics on their practices, and advocate for policies which advance the best interest of those served. In addition, because joining forces through coalitions can multiply the influence for change (Berkowitz & Wolff, 2000), the NKF-CNSW can potentially team up with other professional groups like the NKF Council on Renal Nutrition (CRN), the NKF Council of Nephrology Nurses and Technicians (CNNT), and American Nephrology Nurses Association (ANNA), all of which also have major concerns about staffing. Finally, because patients have been the real victims of inadequate staffing in terms of suffering from its adverse effects (e.g., unaddressed depression and increased infection risks), perhaps the American Association of Kidney Patients (AAKP) would also be interested in joining a political advocacy effort for improvements in this neglected, but critical area of care.

DISCUSSION

There has been an historic tendency in the ESRD program for recommendations to be made and evidenced-based guidelines to be issued (e.g., the KDOQI Clinical Practice Guidelines), with little or no consideration of how they are actually going to be implemented. An Institute of Medicine (1992) report observed the consequences of this, stating, "While guidelines may be meticulously developed and clearly presented they are without value if not successfully applied." Illustrative of this, when the KDOQI Clinical Practice Guidelines for Nutrition were issued (NKF, 2000), it was not remotely considered that renal dietitians would not be able to fully implement the 21 Adult Nutrition Guidelines component, due to inadequate staffing (Burrowes et al., 2005; Vergil & Wolf, 2009). Similarly with nephrology nurses, while the Centers for Disease Control and Prevention (2001) has issued guidelines for preventing infection among ESRD patients, research has shown that nurses are not able to consistently adhere to them, again because of inadequate staffing (Arenas et al., 2005; Shimokura, Weber, Miller, Wurtzel, & Alter, 2006). Finally, with regard to nephrology social workers, while presentations and papers have continued to justifiably tout how these professionals can intervene with depression and other psychosocial problems, little consideration is typically given to how often overwhelmed social workers in dialysis clinics are going to find the time to actually implement what is presented (Bogatz et al., 2005; Callahan et al., 1997; King, 2003; Merighi & Collins, 2011; Merighi & Ehlebracht, 2002; Merighi & Ehlebracht, 2005; Wolfe, 2011). While these broad tendencies have continued, there has been a simultaneous festering of underlying staffing problems with nephrology nurses (O'Brien, 2011; Flynn, Thomas-Hawkins, & Clark, 2009), renal dietitians (Gutekunst, 2012), and nephrology social workers (Merighi & Collins, 2011), that has been largely ignored. This study endeavors to further elevate the staffing issues of nephrology social workers by highlighting their multiple ramifications, and raising questions not previously considered. On the optimistic side, pragmatic strategies are suggested, which could help to mitigate the crisis in staffing,

REFERENCES

Abdel-Kader, K., Unruh, M. L., Weisbord, S. D. (2009). Symptom burden, depression and quality of life in chronic and end-stage kidney disease. *Clinical Journal of the American Society Nephrology, 4*(6), 1057–1064.

Abuelo, J. G. (1998). Large interdialytic weight gains: Causes, consequences and corrective measures. *Seminars in Dialysis, 11*(1), 25–32.

Arenas, M. D., Sanchez-Paya, J., Barril, G., Garcia-Valdecasas, J., Gorriz, J. L., Soriano, A., et al. (2005). A multicenter study of the practice of hand hygiene in hemodialysis units: factors affecting compliance. *Nephrology Dialysis and Transplantation*, *20*(3), 1164–1171.

Ashker, V. E., Penprase, B., & Salman, A. (2012). Work-related emotional stressors and coping strategies that affect the well-being of nurses working in hemodialysis units. *Nephrology Nursing Journal, 34*(3), 231–236.

Bakir, A. A., & Dunea, G. (2001). Renal disease in the inner city. *Seminars in Nephrology, 21*(4), 334–345.

Battistella, M. (2012). Management of depression in hemodialysis. *The Canadian Association of Nephrology Nurses and Technologists Journal, 22*(3), 29–34.

Beder, J., Mason, S., Johnstone, S., Callahan, M. B., & LeSage, L. (2003). Effectiveness of a social work psychoeducational program in improving adherence behavior associated with risk of CVD in ESRD patients. *Journal of Nephrology Social Work*, *22*, 12–22.

Berkowitz, B., & Wolff, T. (2000). *The spirit of the coalition*. Washington, D.C.: American Public Health Association.

Bhat, P. & Bhat, J. G. (2012). Tackling pay-for-performance: Current and future challenges. *Nephrology News and Issues, 26*(1), 27–29.

Blades, B. C. (2010). Social work in a for-profit renal dialysis unit. In T. S. Kerson & J. L. M. McCoyd (Eds.), *Social work in health settings: Practice in context* (pp.167–178). New York: Routledge.

Bogatz, S., Colasanto, R., & Sweeney L. (2005). Defining the impact of high patient/staff ratios on dialysis social workers. *Nephrology News and Issues, 19*(2), 55–60.

Browne, T. (2006). Nephrology social work: History in the making. *Journal of Nephrology Social Work, 25*, 11–29.

Burrowes, J. D., Russell, G. B., & Rocco, M. V. (2005). Multiple factors affect renal dietitians' use of the NKF-K/DOQI Adult Nutrition Guidelines. *Journal of Renal Nutrition*, *15*, 407–426.

Cabness, J., Miller, C., & Martina, K. (2007). Mastering hemodialysis to reverse patterns of missed and shortened treatments. *Journal of Nephrology Social Work, 27*, 45–51.

Callahan, M. B., Moncrief, M., Wittman, J., & Maceda, M. (1998). Nephrology social work intervention and the effect of caseload size on patient satisfaction and rehabilitation interventions. *Journal of Nephrology Social Work, 18*, 66–73.

Callahan, M. B., Witten, B., & Johnstone, S. (1997). Improving quality of care and social work outcomes in dialysis. *Nephrology News and Issues, 11*(2), 40–43.

Centers for Disease Control and Prevention. (2001). Recommendations for preventing transmission of infection among chronic hemodialysis patients. *Morbidity and Mortality Weekly Report, 50*, 1–143.

Centers for Medicare and Medicaid Services (CMS). (2008). Medicare and Medicaid Programs: Conditions for Coverage for End-Stage Renal Disease Facilities; Final Rule 42 CFR Parts 405, 410, 413, et al. 73 *Fed Reg.* 20369 (April 15, 2008). Retrieved from **http://www.gpo.gov/fdsys/pkg/FR-2008-04-15/html/08- 1102.htm**

Daugirdas, J. T. (2012). Dialysis time, survival, and dose targeting bias. *Kidney International, 83*, 9–13.

Davenport, U., Itschaki, N., & Siegal, B. (1993). Adequacy of social work staffing in nephrology: A study. *Nephrology News and Issues, 7*(11), 44, 54, 56, 58.

Department of Health, Education, and Welfare (HEW). (1976). Renal disease: Implementation of coverage of supplies of end-stage services. *Federal Register, 41*(108), 22510–22512.

Department of Health and Human Services (DHHS). (2003). Centers for Medicare and Medicaid Services (CMS) Program: Revisions to payment policies under the physician fee schedule for calendar year 2004. Final rule with comment period. *Federal Register*, *68*, 63195–63395.

Department of Health and Human Services (DHHS). (2012). Centers for Medicare and Medicaid Services (CMS) Program: End-stage renal disease prospective payment system, quality incentive program and bad debt reductions for all Medicare providers. *Federal Register*, *77,* (218), 1–83.

Dolecek ,T. A., Olson, M. B., Caggiula, A. W., Dwyer, J. T., Milas, N. C., Gillis, et al. (1995). Registered dietitian time requirements in the modification of diet in a renal disease study. *Journal of American Dietetic Association, 95*(11), 1307–1312.

Donabedian, A. (1966). Evaluating the quality of medical care. *Milbank Memorial Fund, 44*, 166–203.

Erickson, K. F., Tan, K. B., Winkelmayer, W. C., Chertow, G. M., & Bhattacharya, J. (2013). Variation in nephrologist visits to patients in hemodialysis across dialysis facilities and geographic locations. *Clinical Journal of American Society Nephrology, 8*, 1–8.

Erickson, K. F, Winkelmayer, W. C., Cherton, G. M., & Bhattacharya, J. (2014). Physician visits and 30-day hospital readmission in patients receiving hemodialysis. *Journal of the American Society of Nephrology.* Epub ahead of print retrieved August 15, 2014, from **jasn.asnjournals.org/content/early/2014/05/02/ASN.2013080879.full doi:10.1681/ASN.2013080879**

Fink, J. C., & Henrich, W. L. (2001). The outcome of the urban renal patient: The importance of social factors and center effects. *Seminars in Nephrology, 21*(4), 356–361.

Fischer, M., J., Kimmel, P. L., Greene, T., Gassman, J. J., Wang, X., Brooks, D. H., et al. AASK Study Group. (2010). Sociodemographic factors contribute to the depressive affect among African Americans with chronic kidney disease. *Kidney International*, *77*, 1010–1019.

Fishbane, B., Miller, I., Danko, H., & Masani, N. (2012). The QIP: Will it improve dialysis care? *Nephrology News and Issues, 26*(1), 22–24, 26.

Flynn, L., Thomas-Hawkins, C., & Clark, S. P. (2009). Organizational traits care processes and burnout among chronic hemodialysis nurses. *Western Journal of Nursing Research, 31*(5), 569–582.

Ford, J. M., & Kaserman, D. L. (2000). Ownership structure and the quality of medical care: Evidence from the dialysis industry. *Journal of Economic Behavior and Organization, 43*, 279–293.

Foster, M. (2008). Treating patients with CKD who are violent or homeless: A need for further study. *Nephrology Nursing Journal, 35*(1), 96.

Gardner, J. K., Thomas-Hawkins, C., Fogg, L., & Latham, C. E. (2007). The relationship between nurses' perception of the hemodialysis unit work environment and nurse turnover, patient satisfaction, and hospitalization. *Nephrology Nursing Journal, 34*(3), 271–281.

Gordon, E. J., Leon, J. B., & Sehgal, A. R. (2003). Why are hemodialysis treatments shortened and skipped? Developing a taxonomy and relationship to patient subgroups. *Nephrology Nursing Journal, 30*(2), 209–217.

Greipp, M. E. (2002). Forces driving healthcare policy decisions. *Policy, Politics, and Nursing Practice, 3*(1), 35–42.

Grieco, P., & McDevitt, R. C. (2012). Production and quality in healthcare: Evidence from the dialysis industry. [working paper]. Retrieved February 10, 2013 from **http://scholm.google.com/scholar?hl=grieco+o2c+mcdevitte**

Gutekunst, L. (2012). Call to arms. *Journal of Renal Nutrition, 22*(1), 72–74.

Hall, M. A., & Conover C. J. (2006). For-profit conversion of Blue Cross plans: Public benefit or public harm? *Annual Review of Public Health, 27*, 443–463.

Harley, K. T., Streja, E., Rhee, C. M., Molnar, M. Z., Kovesdy, C. P., Amin, A. N., & Kalantar-Zadeh, K. (2013). Nephrologist caseload and hemodialysis patient survival in an urban cohort. *Journal of the American Society of Nephrology, 24*(10), 1678–1687.

Hegde, A. V., Vels, J. H., Seidman, A., Khan, S., & Moore, J. Jr. (2000). High prevalence of alcoholism in dialysis patients. *American Journal of Kidney Diseases, 35*(6), 1039–1043.

Himmelfarb, J., Berns, A., Szczech, L., & Wesson, D. (2007). Cost, quality and value: The changing political economy of dialysis care. *Journal of the American Society of Nephrology, 18*, 2021–2027.

Hoffart, N., & Nissenson, A. R. (1998). The future of end-stage renal disease care: Nephrology enters a new millennium. *Advances in Renal Replacement Therapy, 5*(4), 257–266.

Institute of Medicine. (1992). *Guidelines for clinical practice.* Washington, D.C.: National Academy Press.

Johnstone, S. (2007). Depression management for hemodialysis patients: Using DOPPS data to further guide nephrology social work intervention. *Journal of Nephrology Social Work, 26*, 18–31.

Johnstone, S., & Halshaw, D. (2003). Making peace with fluid: Social workers lead cognitive behavioral intervention to reduce health-risk behavior. *Nephrology News and Issues, 17*, 13, 20–27, 31.

Just, P. M., de Charro, F. T., Tshosik, E. A., Noe, L. L. Bhattacharyya, S. K., & Riella, M. C. (2008). Reimbursement and economic factors influencing dialysis modality choice around the world. *Nephrology Dialysis Transplantation, 23*(7), 2365–2373.

Kalantar-Zadeh, K., Regidor, D. L., Kovesdy, C. P., Van Wych, D., Bunnapradist, S., Horwich, T. B., et al. (2009). Fluid retention is associated with cardiovascular mortality in patients undergoing long-term hemodialysis. *Circulation, 119*(5), 671–679.

Kimmel, P. L., Fwu, C. W., & Eggers, P. W. (2013). Segregation, income disparities, and survival in hemodialysis patients. *Journal of the American Society Nephrology, 24*(2), 93–301.

Kimmel, P. L., & Peterson, R. A. (2008). Depression in patients with end-stage renal disease treated with dialysis: Has the time to treat arrived? *Clinical Journal of the American Society Nephrology, 1*(3), 349–352.

King, K. (2003). The inside word on communication in the dialysis unit. *Family Focus, 12*(4), 1–2.

Kucirka, L. M., Grams, M. E., Lessler, J., Hall, E. C., James, N., Massie, A. B., et al. (2011). Association of race and age with survival among patients undergoing dialysis. *Journal of the American Medical Association, 306*(6), 620–626.

Kutner, N., Bowles, T., Zhang, R., Hung, Y., & Pastan, S. (2008). Dialysis facility characteristics and variations in employment rates: A national study. *Clinical Journal of American Society Nephrology, 3*(1), 111–116.

Lacson, E. Jr., & Brunelli, S. M. (2011). Hemodialysis treatment time: A fresh perspective. *Clinical Journal of the American Society of Nephrology, 6*(16), 2522–2530.

Lopes, A. A., Albert, J. M., Young, E. W., Satayathum, S., Pisoni, R. L., Andrevcci, V. C., et al. (2004). Screening for depression in hemodialysis patients: Association with diagnosis, treatment, and outcomes in the DOPPS. *Kidney International, 66*(5), 2047–2953.

Mark, B. A., Harless, D. W., Spetz, J., Reiter, K. L., & Pink, G. H. (2013). California's minimum nurses staffing legislation: Results from a national experiment [Part 1]. *Health Services Research, 48*(2), 435–454.

Mentari, E. K., DeOreo, P. B., O'Connor, A. S., Love, T. E., & Sehgal, A. R. (2005). Changes in Medicare reimbursement and patient-nephrologist visits, quality of care and health-related quality of life. *American Journal of Kidney Diseases, 46*(4), 621–627.

Merighi, J. R., Browne, T., & Bruder, K. (2010). Caseloads and salaries of nephrology social workers by state, ESRD Network, and National Kidney Foundation Region: Summary findings for 2007 and 2010. *Journal of Nephrology Social Work, 34*, 9–51.

Merighi, J. R., & Collins, K. (2011). Critical concerns and challenges in nephrology social work practice: Reactions to the 2008 Conditions for Coverage. *Journal of Nephrology Social Work, 35*, 9–16.

Merighi, J. R., & Ehlebracht, K. (2002). Changing roles and responsibilities of nephrology social workers: Are they appropriate? *Nephrology News and Issues, 16*(5), 59, 74.

Merighi, J. R., & Ehlebracht, K. (2004). Unit-based patient services and supportive counseling provided by renal social workers in the U.S. *Nephrology News and Issues, 18*(7), 55, 59–63.

Merighi, J. R., & Ehlebracht, K. (2005). Emotional exhaustion and workload demands in renal social work practice. *Journal of Nephrology Social Work, 24*, 14–20.

Meyer, K. B., & Kassirer, J. R. (2002). Squeezing more cost and care out of dialysis: Our patients would pay the price. *American Journal of Medicine, 112*, 232–234.

National Association of Social Workers (NASW). (2008). *Code of ethics.* Retrieved from **http://www.naswdc.org/pubs/code/codeeasp**

National Kidney Foundation (NKF). (2000). KDOQI clinical practice guidelines for nutrition in chronic renal failure. *American Journal of Kidney Diseases, 39*(Suppl 2), S1–S140.

National Kidney Foundation Council of Nephrology Social Workers (NKF-CNSW). (1987). *Practice guide for nephrology social work.* New York: National Kidney Foundation.

National Kidney Foundation Council of Nephrology Social Work (NKF-CNSW) Executive Committee (1989). Quality and accessibility of social work services to dialysis patients: A study. *Nephrology News and Issues, 3*(12), 26, 27, 31, 32, 36.

Obialo, C. I., Bashir, K., Garing, S. Robinson, B., Quarshie, A., Al-Mahmoud, A., et al. (2008). No-shows on Saturdays: Implications of the weekly hemodialysis schedules on nonadherence and outcomes. *Journal of the National Medical Association, 100*(4), 412–419.

Obialo, C. I., Hunt, W. C., Bashir, K., & Zager, P. G. (2012). Relationship of missed and shortened hemodialysis treatments to hospitalization and mortality: Observations from a U.S. dialysis network. *Clinical Kidney Journal, 5*, 315–319.

O'Brien, J. L. (2011). Relationships among structural empowerment, psychological empowerment, and burnout in registered staff nurses working in outpatient dialysis centers. *Nephrology Nursing Journal, 38*, 475–481.

Pace, R. C. (2007). Fluid management in patients on hemodialysis. *Nephrology Nursing Journal, 34*(5), 557–559.

Patzer, R. E., Perryman, J. P., Schrager, J. D., Pastan, S., Amaral, S., Gazmararian, J. A., et al. (2012). The role of race and poverty in steps to kidney transplantation in the Southern United States. *American Journal of Transplantation, 12*, 358–368.

Peace, L. (personal communication) April 12, 2013.

Plantinga, L. C., Fink, N. E., Harrington-Levey, R., Finkelstein, F. D., Hebah, N., Powe, N. R., et al. (2010). Association of social support with outcomes in incident dialysis patients. *Clinical Journal of American Society Nephrology, 5*, 1480–1488.

Plantinga, L. C., Jaar, B. C., Fink, N. E., Sadler, J. H., Levin, N. W., Coresh, J., Klag M. J. & Powe, N. R. (2005). Frequency of patient-physician contact in chronic kidney disease care and achievement of clinical performance targets. *International Journal of Quality in Healthcare, 17*(2), 115–121.

Priest, C. (2012) Advocacy in nursing and healthcare. In D. J. Mason, J. K. Leavitt & W. Chaffer (Eds). *Policy and politics in nursing and healthcare* (pp. 31-38). St. Louis, MO: Elsevier.

Rahman, M., Fu, P., Sehgal, A. R., & Smith, M. C. (2000). Interdialytic weight gain, compliance with dialysis regiment, and age are independent predictors of blood pressure in hemodialysis patients. *American Journal of Kidney Diseases, 35*(2), 257–265.

Renal Business Today. (2013). Fresenius wins Modern Healthcare Award for quality of life program. Retrieved June 1, 2013 from **http://www.renalbusiness.com/news/2013/05/fresenius-wins-modern-healthcare-award-for-qualit.aspx**

Rettig, R. A., & Levinsky, N. E. Institute of Medicine. (1991). *Kidney failure and the federal government.* Washington, D.C.: National Academy Press.

Rosner, M., Abdel-Rahman, E., Williams, M. E. (2010). Geriatric nephrology: Responding to a growing challenge. *Clinical Journal of the American Society Nephrology, 5*, 936–942.

Russo, R. (2002). The role of the renal social worker in the 21st century. *Nephrology News and Issues, 16*(3), 38, 40.

Santos, P. R., & Arcanjo, F. P. (2013). Social adaptability and substance abuse predictors of depression among hemodialysis patients? *BMC Nephrology.* Jan 15, 14:12 doi:10. 1186/1471-2369-14-12.

Saran, R., Bragg-Gresham, J. L., Rayner, H. C., Goodkin, D. A., Keen, M. L., Van Dijk, P. C., et al. (2003). Nonadherence in hemodialysis: Associations with mortality, hospitalization and practice patterns in the DOPPS. *Kidney International, 64*, 254–262.

Saxena, A. K., & Panhotra, B. R. (2004). The impact of nurse understaffing on the transmission of hepatitis C virus in a hospital-based hemodialysis unit. *Medical Principles and Practice, 13*(4), 129–135.

Sehgal, A. R., Grey, S. F., DeOreo, P. B., & Whitehouse, P. J. (1997). Prevalence, recognition, and implications of mental impairment among hemodialysis patients. *American Journal of Kidney Diseases, 30*(1), 41–49

Sehgal, A. R., Snow, R. J., Singer, M. E., Amini, S. B., DeOreo, P. B., Silver, M. B., et al. (1998). Barriers to adequate delivery of hemodialysis. *American Journal of Kidney Diseases, 31*(4), 593–601.

Shimokura, G., Weber, D. J., Miller, W. C., Wurtzel, H., & Alter, M. J. (2006). Factors associated with personal protection equipment use and hand hygiene among hemodialysis staff. *American Journal of Infection Control, 34*, 100–107.

Shotan, A., Dacca, S., Shochat, M., Kazatsker, M., Blondheim, D. S. & Meisel, S. (2005). Fluid overload contributing to heart failure. *Nephrology Dialysis and Transplantation, 20* (Suppl 7), vil24–vil27.

Siegal, B. R., Witten, B., & Lundin, A. P. (1994). Patient access and expectations of nephrology social workers. *Nephrology News and Issues, 8*(4), 32–33, 40.

Slinin, Y., Guo, H., Li, S., Liu, J., Ensrud, K., Gilbertson, D. T., et al. (2012). Association of provider-patient visit frequency and patient outcomes on hemodialysis. *Journal of the American Society of Nephrology, 23*, 1560–1567.

State of Texas. Department of State Health Services Regulatory Licensing Unit Facility Licensing Group. (2010). Title 25 Texas Administrative CODE. Chapter 117. End-Stage Renal Dialysis Facilities Licensing Rules. Retrieved from **http://www.esrdnetwork.org/assets/pdf/regulations/2010_esrdruleschapter117_07_2010.pdf**.

Sullivan, J. D. (2009). Economic correction and the potential impact on the dialysis industry. *Nephrology News and Issues, 23*(8), 14–16.

Tapolyia, M., Fulop, T., Uysal, A., Lengvarszky, Z, Szarvas, T., Ballard, K., et al. (2010). Regional differences in nonadherence to dialysis among Southern dialysis patients: A comparative cross-sectional study to the Dialysis Outcomes and Practice Patterns Study (DOPPS). *American Journal of Medical Sciences, 339*(6), 516–518.

Thong, M. S. Y., Kaptein, A. A., Krediet, R. T., Boeschoten, E. W., & Dekker, F. W. (2007). Social support predicts survival in dialysis patients. *Nephrology Dialysis and Transplantation, 22*, 845–850.

Vergil, J. M., & Wolf, R. L. (2009). Nutrition practices of renal dietitians in hemodialysis centers throughout the United States: A descriptive study. *Journal of Renal Nutrition, 20*, 8–16.

Watnick, S., Kirwin, P., Mahnensmith, R., & Concato, J. (2003). The prevalence and treatment of depression among patients starting dialysis. *American Journal of Kidney Diseases, 41*, 105–110.

Wellington, M. R. (2000). Hemodialysis and homelessness: A literature review and call for research. *Nephrology Nursing Journal, 27*(3), 305–310.

White, R. B. (2004). Adherence to the dialysis prescription: Partnering with patients for improved outcomes. *Nephrology Nursing Journal, 31*(4), 432–435.

Wolfe, W. A. (2011). Adequacy of dialysis clinic staffing and quality of care: A review of evidence and areas of needed research. *American Journal of Kidney Diseases, 58*(2), 166–176.

Wolfe, W. A. (2012). Moving the issue of renal dietitian staffing forward. *Journal of Renal Nutrition, 22*(5), 515–520.

Wolfe, W. A. (in press). Are word-of-mouth communications contributing to a shortage of nephrology nurses? *Nephrology Nursing Journal.*

The Experience of Mothering a Child with a Kidney Transplant and the Implications of Illness-Related Uncertainty

Andrew Mantulak, MSW, PhD, RSW,
Assistant Professor, King's University College at Western University, London, ON, Canada

Advances in the surgical and immunological aspects of organ transplantation have resulted in significant improvements in long-term outcomes and survival rates, making kidney transplantation the optimal therapy for children with chronic kidney disease (CKD). This study examines the phenomenon of ***sustained uncertainty*** *as an element of the burden of care for maternal caregivers of children who have undergone kidney transplantation. This study indicates these mothers experience uncertainty in two prominent ways: 1) in their subjective sense of time, and 2) in their ongoing fear that their child will experience rejection of the transplanted kidney. Ultimately, this study advocates for nephrology social workers to begin addressing the social and emotional implications of uncertainty in the experience of illness for caregivers.*

INTRODUCTION

Parenting a child with chronic kidney disease (CKD) is understood to have a profound impact on both the ailing child and the family across the bounds of social, emotional and physical functioning (Aldridge, 2008; Tong, Lowe, Sainsbury, & Craig, 2008). Relatedly, advances in the surgical and immunological aspects of organ transplantation have resulted in significant improvements in long-term outcomes and survival rates, making kidney transplantation the optimal therapy for children with CKD (Anthony et al., 2010). The goal of transplantation is no longer simply graft survival and getting children to an acceptable level of physical health, but to improve their overall quality of life.

Despite the anecdotal "successes" of transplants allowing children to live independent of dialysis and enjoy an improved quality of life, the literature reflects parents' feelings that the transplant period brings another myriad set of challenges with which they must contend. Tong et al. (2008) found that parents of children receiving a transplant reported experiencing similar emotions to those whose children were on dialysis, but also struggled with the uncertainty posed by the potential rejection of the kidney graft. The documented narratives of caregivers of children post-kidney transplant indicate that, once the parents have survived the reality of their child's organ failure and subsequent transplant, they must manage the increased risk of their child's susceptibility to illness (Merskhani, 2007). These responsibilities include supporting the child through possible side effects of medications, painful biopsies necessary to assess and treat rejections, hospitalizations, and school reintegration. These are care responsibilities that differ from the particular restrictions and demands associated with dialysis, but are, nonetheless, intrusive and time consuming. In addition, there is evidence that even when children are deemed as clinically "doing well," families report a continuing struggle with the restrictions, imposed limitations, and the intrusions and management of CKD in their daily functioning (Anthony et al., 2010). Sundaram, Landgraf, Neighbors, Cohn, and Alonso (2007) studied 26 adolescent kidney transplant recipients and reported that "caregivers expressed significant negative emotional impact from their child's health condition and on their family activities" (p. 986).

One of the primary challenges associated with caregiving for this population of patients is the implication of illness-related uncertainty. This paper reports on the findings regarding sustained uncertainty from a recent research study that explored the lived experience of maternal caregivers of children who had undergone kidney transplantation. Existing literature does highlight that transplantation is fraught with various forms of uncertainty, including such worries as: "How long is the wait for transplant?"; "Will the procedure be successful?"; "Will the transplant make a difference in the life of the patient?"; and "If the transplant is successful, will the benefits of the procedure outweigh the risks?" (Martin, Stone, Scott, & Brashers, 2010). Several studies that deal with the adult population confirm a strong association of uncertainty with psycho-emotional distress (Mishel, 1999). Although uncertainty has been acknowledged and studied in the context of those waiting for transplant or receiving one, less is known about the role of uncertainty during the entire trajectory of the transplant experience. Overall, existing evidence suggests that uncertainty undermines quality of life and is strongly associated with increased stress and decreased life satisfaction (Mishel, 1999). Research has found that the impact of uncertainty is embedded in the caregiver's experience of the temporal sense of time, and exists within their ongoing fear of their child's rejection of the transplanted organ.

METHOD

Approach to Research

This research utilized a hermeneutic phenomenological approach to examine the lived experience of mothers of children who had undergone kidney transplantation.

Direct correspondence to: Andrew Mantulak, MSW, PhD, RSW, Assistant Professor, King's University College at Western University,
266 Epworth Avenue, London, ON, Canada, N6A 2M3; 519.433.3491 ext. 4588; **amantula@uwo.ca**

Phenomenology, as a method of social science research, aims at gaining a deeper understanding of the nature or meaning of everyday experiences (Husserl, 1970; Van Manen, 1990). Hermeneutic phenomenology is concerned with the "life world" (or human experience as it is lived) where the focus is on "illuminating details and seemingly trivial aspects within experience that may be taken for granted in our lives, with a goal of creating meaning and achieving a sense of understanding" (Wilson & Hutchinson, 1991, p. 34). The purpose of the phenomenological approach is to identify phenomenon through the perception of individuals located in a specific situation (Lester, 2010).

Participants

Seven mothers shared their experiences of pediatric kidney transplantation, beginning with the first time they became aware that their child had CKD. The mothers ranged in age from 27 to 41 years of age; the children ranged from 6 to 17 years of age. At the time of the study, 5 of the children were 3 to 5 years post-transplant, one was at the 1-year mark and one had been successfully transplanted for 15 years. All 7 children had only been transplanted one time and all had been diagnosed with CKD within their first year of life. Six of the 7 participants were married and residing with the biological father of the transplanted child. All of the participants lived in the Southwestern Ontario, Canada region. This research was reviewed and approved by the Office of Research Ethics at Wilfrid Laurier University. Consistent with research ethics guidelines, measures were taken to ensure confidentiality of data and personal health information, and anonymity of participants. Informed written consent was obtained from all participants.

Data Collection

Data collection procedures were designed to obtain in-depth narratives of the experience of pediatric kidney transplantation from participant mothers in a manner that enabled the exploration of the phenomena from their constructed reality and associated meanings. For this purpose, in-depth, semi-structured interviews were utilized as an instrument of inquiry, consistent with the phenomenological method.

FINDINGS

Time as Uncertain

The mothers' narratives described lives filled with unknowns, which necessitated that they learn how to mentally and emotionally manage this uncertainty. Their lives become defined by an acute sense of time and their feelings of suspension, anxiety, and worry related to its passing. For these mothers, the experience of having a child with a kidney transplant meant learning to live with and be comfortable with uncertainty, because they never can know when a sudden and intrusive change in their childrens' lives might happen.

Coping with uncertainty was a prominent aspect of their experience. One participant recalled, "My mind is already fast forwarded 15 years from now, and I want to know, I'm already stressed out now knowing what's the kidney for him (sic) and where is it going to come from?" Another confided that, "You're always thinking about the 'what ifs.' He goes to camp this summer. What if he doesn't get his medications? It's the day-to-day worry about what could happen and what tomorrow will bring that becomes part of what you always think about." Even when things were going well, the unknowns associated with the future were always in the forefront of their thoughts: "I mean, to me it's like very calm right now, but there's that piece in the back of your mind going, when's it going to hit the fan again? Like you're always worried for that, like that constant little 'what if?'"

The participants also talked about the importance of becoming comfortable with the unknowns as an essential element of coping with uncertainty, or, as one participant described it, the "greys." She explained:

> ...that even though it is black and white on paper, there's always going to be grey areas no matter what it is. I have not run into one person that hasn't had a little bit of grey area somewhere, and just knowing that, you know, that it's going to be up and down no matter what for how long, for the next 30 years it can be up and down.

The ability to make meaning from their unpredictable situations is represented in the mothers' quests to come to terms with the chronic nature of the uncertainty in their lives.

Time as Living in the Moment

Time was an essential feature of the experience in relation to the presence of suspended time, time as "waiting," and the notion of past, present, and future. Embedded in the lived experience of transplant day was the mothers' sense of waited time as their children, and in some cases significant others, were in the operating room. For some of the participants, the day of transplant, in terms of temporality, was described as going by fast: "The day of the transplant seemed to go by very fast. I didn't feel like I did a lot of waiting around at all; that surprised me." For others, however, the length of time spent waiting during the actual procedure was considered a difficult period within the experience: "I'm sitting there waiting. That was brutal, you know, it was eight hours but it felt like twelve"; "The waiting part was really hard. Time really seemed to drag, but I do remember right after the surgery was a relief"; and "It's like a long time to wait—especially when there is no communication from anyone for hours at a time."

For others, time was notably experienced in the monitoring and giving of medications so emblematic of post-transplant care:

> Yeah it is hard, and then being paranoid about med times. Okay make sure you get this at this time and at this time, and at that time he was on

> three doses a day because he was so little… so we had to wake up in the night to have the one dose because they all had to be 8 hours apart. So to try to manage it all. Sure, then you have to make sure, okay, wherever you are going to be you have all the meds you need and know what time it is. You can't vary even, you know, just a little bit, in case he rejects.

The awareness of time also extended to the hospital environment, where time and its passing, with little control of what it may bring, is not far from their minds: "No showering, feeling like, you know, just sitting there waiting on answers, waiting on blood work, holding him down to do blood work, putting him on IV, watching TV all day, just sitting there and looking and feeling like a zombie."

For the participants in this study, the lapsing of time served to structure their experiences as caregivers and was something that they needed to find ways to cope with and make meaning of on almost a daily basis. For these participants, then, uncertainty meant living in the moment: "[There is] not much you can do about it. It is what it is," and "[You] just have to be thankful for how well he feels right now and know it could change but can't worry about it all the time." Making meaning of the uncertainty and lack of control over one's own time was a major challenge for this group of caregivers.

Time as Fear of Rejection of the Transplanted Organ

The most prominent form of uncertainty in the mothers' lives surrounded the eventual rejection of the transplanted kidney. This reality impacted every aspect of their lives, and their daily rituals were embedded with the fear of transplant rejection. As one mom emphatically noted in our interview, "Is rejection always in my head? Absolutely, it is there every day, absolutely." Kidney rejection was a constant worry for the mothers:

> Like from the minute she [the child] gets transplanted to the minute of every day you think, ok, am I going to get a call that, you know, something's not right. She's gotta come in and we will find out she's rejecting?

For several of the participants, drastic, life-altering change was always around the corner:

> You always have that fear that he [the child] is going to lose it. Rejection is really, really nerve wracking for me and I am always thinking okay, when is this one going to be toast and we have to move on to the next one?

The fear that the kidney would fail was never far from the minds of these caregivers and it is a source of much stress and anxiety, ever-present throughout the life of child with the transplanted kidney. The experience of uncertainty and organ rejection meant living on the "margins" of the child's good health that was experienced in-between the "here and now," and the threat of future loss.

The fear of kidney rejection was grounded in the mothers' realization of the implications of losing the transplanted kidney for their children. For most participants, it meant a return to dialysis for their child. "Yeah, I always worry that something's going to happen for my child. It's horrible and I hate the feeling that one day that he might reject it and we'll be in the hospital again and we'll be living off a dialysis machine," confided one mother. As a result, even something as simple as going to the hospital for a routine clinic visit became a source of anxiety, since "every time you go in the hospital you don't know how it's going to flip. You don't know how that's going to turn out and you will be required to stay overnight or for a month." The result was that the participants' daily lives were imbued with the anxiety that is created by the threat of organ rejection and, as such, a major challenge with which they must emotionally and psychologically cope.

To that end, a source of frustration for several participants was encountering individuals who projected onto mothers' the sense that they should be feeling relief that their child had been transplanted and the perceived freedom from the responsibilities of pre-transplant care:

> I mentioned to a friend the other day that [my daughter] had a kidney transplant and she said, "Oh well she got a transplant, guess you're happy she'll be good for the rest of her life?" It's like, no, she's on medication every single day of her life for the rest of her life, and you don't know when. This kidney could last her for 20 years or it could be gone tomorrow. You don't know.

The struggle against the social misunderstanding of transplant as a "cure" versus a treatment was a challenge echoed by several participants in this study.

DISCUSSION

The findings of this study highlight that uncertainty begins at the time of diagnosis and continues throughout all stages of a child's development and treatment of their CKD. Although a definitive diagnosis might bring a sense of assurance of what lies ahead for some patients who are facing chronic illness, the mothers in this study painted quite a different picture of what constitutes uncertainty in their families' lives. As a therapy, transplantation means a tenuous future that is reliant on timelines for transplant, as well as the managed prevention of organ rejection.

In the context of the lived experience of mothers whose children had undergone a kidney transplant, it becomes difficult to talk about the implications of living with sustained uncertainty without relating it to temporality (as it exists as an existential element of experience). Temporal time—as it relates to past, present, and future—structures our lives and becomes part of our temporal experience of living. The dimensions of time serve to create our personal sense of continuity in life (as most events organized in this way become the timeline of one's life). Such a timeline typically constitutes developmental milestones such as birth, graduations, marriage, and the introduction of children, to name a few. For the population of caregivers with chronically ill children, this timeline becomes disrupted with the news of the diagnosis, "as it challenges the very sense of continuity that time consciousness constitutes" (Woodgate & Degner, 2002, p. 24). As a result, the timeline continuity for the child becomes warped, and, essentially, the transplant signifies the beginning of a new life with an unpredictable and different future. This disruption of a "normal" timeline is evident in the participants' narratives about the ongoing unpredictability of illness and the uncertainty attached to the future. The temporal consequence for participants, then, is that they expressed becoming existentially trapped in a future that belongs to the changing needs of the present.

Uncertainty is also closely tied with the significant amount of time the women spend in suspended or waiting time. This "suspended time" includes the time that is taken up waiting for clinic visits, waiting for phone calls about blood work and test results, and the period of time leading up to and during the transplantation procedure. These mothers describe how much of this waited time is the result of a system of healthcare that has its own timelines and delivery procedures. For these mothers, this suspended time is also imbued with uncertainty related to the possibility of poor blood work results, potential necessity of hospitalization, further testing, or changes to medication regimen. Waited time becomes part of the daily reality for these individuals and they perceive that a significant period of their life is spent "waiting and wondering." As with other uncertainties associated with transplant, these mothers are aware that the unexpected can occur on any day (i.e., a poor blood work result that will require hospitalization, or even a rejection of the transplanted kidney). The uncertainty associated with waiting, therefore, is the source of great stress and anxiety. Despite the difficulties of this reality as expressed in the mothers' narratives, however, this waited time and its impact on these women and their families is significantly disregarded by healthcare providers.

Martin et al. (2010) studied uncertainty across the transplant trajectory in adult patients and identified that uncertainty came in medical, social and personal forms. One significant finding in their study was how uncertainty during the post-transplant period was related to amount of time that had passed since transplant. The importance of "time passing" (or passage of time), however, is not without anxiety: "the reality that the longer time without rejection, however, does not exclude the possibility of future rejection" (p. 54). This reality was notable for the mothers in this study, because their narratives reveal that they give little credence (in terms of "success") to the amount of time that has passed since their child's transplant. The passing of "time since transplant" was a notable element of experience, but not necessarily one that was celebrated and embraced as a sign of ongoing success, for many of these mothers. Instead, the longer the time period that passed since the transplant, the closer the mothers felt they were to returning to dialysis and a repeat transplantation.

In essence, the way that these mothers chose to cognitively manage this tension of time since transplant was likened to "the glass being half-full or half-empty." It is important to note that the mothers had to negotiate and manage the messages they received from people who may view a kidney transplant as the end of the journey. Several mothers spoke about their feelings of frustration when friends and neighbors asked them why they were not more content or celebrating the transplant as a victory. During this part of the interview process, the participants became noticeably agitated as they spoke about having to deal with people who did not understand that transplant was not a time to rest their fears, because tomorrow was still filled with uncertainty and ongoing challenges related to managing their child's health. As Martin et al. (2010) noted, in the face of transplant, "uncertainty does not wane over time, it is constant" (p. 232). This contention highlights the reality that the social discourse of "transplant as cure" does not take into consideration the uncertainty embedded in the experience. While transplant is a significant step in providing a child with a better opportunity for an improved quality of life, the experience nevertheless contains many unknowns which maternal caregivers must cognitively and emotionally manage.

The uncertainty they experience, as noted by Cohen (1993), goes beyond simple "not knowing," because the mothers anticipate change in the future, but are uncertain as to when it will occur. In the case of pediatric kidney transplantation, uncertainty carries similar fears relative to the trials and tribulations associated with dialysis. I believe it is difficult to fully appreciate the salient elements that contribute to the fear of rejection without acknowledging its association with the experience of dialysis; however, the nature of this relationship is beyond the scope of this study.

LIMITATIONS OF THE STUDY

This study has several limitations. First, the findings reflect only the experiences of the 7 women who voluntarily participated and therefore cannot be generalized to reflect the experience of all women who act as caregivers to children with kidney transplants. Second, this research focused solely on the perceptions, thoughts, and feelings of these 7 women and did not take into account the experience of siblings, partners, or the transplanted children themselves. Third, the researcher had a previous clinical experience with this population of caregivers, which may have influenced elements of the research process, including the development of the interview schedule, data collection, and analysis. Alternatively, the researcher's familiarity with the women in this study and clinical experience of this population may have offered benefits to the project, including engagement with participants and an appreciation for their experience as caregivers.

IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH DIRECTIONS

For social workers providing service in the area of pediatric nephrology, the findings from this study have far-reaching implications for practice. For one, the results of this study can be used toward the development of an approach to practice that recognizes the challenges and implications posed by the presence of sustained uncertainty that surrounds the experience of caregiving for a child who has had a kidney transplant. Through the course of providing adjustment and supportive counseling, social workers can, with caregivers, acknowledge and validate the presence of uncertainty as a major challenge inherent in the disease process itself. By doing so, they will be able to enable individuals to move toward the development of healthy coping strategies as a means to decrease or manage the uncertainty and challenges. Such strategies may include increased education about uncertainty, facilitating caregivers to assume a more active role in care decisions, or assisting to initiate connections with others who have been through the experience. Uncertainty is an element of the caregiving experience in pediatric transplantation that is identified in the professional literature, but is a topic that rarely gets discussed in the clinical setting.

A topic for future research in the area of uncertainty as it pertains to caregivers of children with kidney transplants may be the link between sustained uncertainty and positive personal growth. As Mishel (1999) asks, does this uncertainty for these mothers lead to a process of rediscovering oneself on some level and making meaning of the experience? Mishel suggests that perhaps these mothers redefine themselves and their abilities, strengths, and attributes in a more positive way amid the challenges of caregiving. To that end, an identified area for future research lies in the further exploration of this link between managing the uncertainty embedded in the pediatric kidney transplant experience and also uncertainty's role as a catalyst for positive personal growth for caregivers.

CONCLUSION

It is well-documented that the experience of caring for a child post-kidney transplant creates for maternal caregivers a myriad of social, emotional, and practical challenges. Anecdotal evidence suggests that uncertainty, as it found in the experience of solid organ transplant, is not a new concept for nephrology social workers, but little research exists in pediatric nephrology that points to uncertainty as an area of clinical importance for social workers as we support and intervene with caregivers of pediatric CKD patients. This study identified that the social and emotional implications of uncertainty for caregivers of pediatric kidney transplants is a daily challenge, and one that needs greater attention in the clinical environment as an element of caregiving experience that has the potential to impact clinical outcomes of transplanted children.

REFERENCES

Aldridge, M. D. (2008). How do families adjust to having a child with chronic kidney failure? A systematic review. *Nephrology Nursing Journal, 35*(2), 157–162.

Anthony, S. J., Hebert, D., Todd, J., Korus, M., Langlois, V., Pool, R., et al. (2010). Child and parental perspectives of multidimensional quality of life outcomes after kidney transplantation. *Pediatric Transplant, 14*, 249–256.

Cohen, M. H. (1993). The unknown and the unknowable: Managing sustained uncertainty. *Western Journal of Nursing Research, 15,* 77–96.

Husserl, E. (1970). *The idea of phenomenology.* The Hague: Martinus Nijhoff.

Lester, S. (2010). *An introduction to phenomenological research*. Retrieved March 2013 from **http://www.psyking.net/HTMLobj-3825/Introduction_to_Phenomenological_Research-Lester.pdf**

Martin, S. C., Stone, A. M., Scott, A. M., & Brashers, D. E. (2010). Medical, personal, and social forms of uncertainty across the transplantation trajectory. *Qualitative Health Research, 20*(2), 182–196.

Mishel, M. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, *17*(1), 269–294.

Merskhani, V. (2007). *The long-term effects of PTSD and anxiety or depression among parents of pediatric organ transplant recipients.* Los Angeles: Alliant International University. ProQuest, UMI Dissertations, 3305632.

Sundaram, S. S., Landgraf, J. M., Neighbors, K., Cohn, R. A., & Alonso, E. M. (2007). Adolescent health related quality of life following liver and kidney transplantation. *American Journal of Transplantation, 7,* 982–989.

Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2008). Experiences of parents who have children with kidney disease: A systemic review of qualitative literature. *Pediatrics*, *121,* 349–360.

Van Manen, M. (1990). *Researching lived experience: Human science for an action-sensitive pedagogy*. Albany, NY: State University of New York Press.

Wilson, H., & Hutchinson, S. (1991). Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research, 1*, 263–276.

Woodgate, R. L., & Degner, L. F. (2002). "Nothing is carved in stone!": Uncertainty in children with cancer and their families. *European Journal of Oncology Nursing, 6*(4), 191–202.

Nonadherence in Individuals on Hemodialysis: A Discussion of Three Theories to Improve Adherence

R. Lee Phillips, LCSW
The University of Georgia, Athens, GA

This paper explores three theories that can guide practice when working to improve the compliance of individuals on hemodialysis. The Theory of Planned Behavior (TPB), the Common-Sense Model (CSM), and Motivational Interviewing (MI) each offer insight into behavioral change and the internal processes of individuals. Each theory seeks to empower the individual and sees client involvement as critical to patient care and improved health-related outcomes. Understanding the tenants of these three theories can guide social work practice beyond education and the dissemination of health-related information in order to improve compliance.

Theories attempt to make sense of interrelated phenomena, help explain how social problems emerge, guide design of interventions, and guide design of policy (Engel & Schutt, 2009). In this paper, three theories are discussed that can offer insight into improving adherence in individuals with end-stage renal disease (ESRD). The discussion of theory is driven by a value of patient empowerment. “Patient empowerment is centered on the belief that patients should be in control of their own care and that behavioral changes and adherence to therapies cannot be achieved unless the patient internalizes the need for self-change” (McCarley, 2009, p. 409). Empowerment is central to social work and reminds us that the client is a person, who needs to be involved in his own care, and is capable of making decisions. Though healthcare professionals in various fields hold an abundance of knowledge on subject matter, the individuals they work with have control of their lives and must make the choices to utilize that knowledge and follow recommended treatment regimens. Ajzen, Joyce, Sheikh, and Cote (2011) point out that:

> Many educational campaigns especially in the health domain, are focused on imparting accurate factual information of a general nature. It is expected that once people have a good understanding of the issues, they will engage in socially or personally desirable behavior. Unfortunately, more often than not, this approach results in failure, and people continue to take unnecessary risks or engage in socially undesirable behavior. (p. 116)

Therefore, something more than education and accurate knowledge is needed to assist behavioral change in individuals.

While many treatments require adherence to strict regimens, Karalis, Wiesen, and Brommage (2007), using an example of dietary restrictions, warn healthcare providers that “resistance to change occurs because we often prescribe the diet that the patients should follow and then try to persuade them to change. We are often too ‘task-oriented’ and may disregard the patients and their willingness or unwillingness to change” (p. 336). The Theory of Planned Behavior (TPB), Common Sense Model (CSM), and Motivational Interviewing (MI) are three theories that can guide social workers working with individuals to bring about the behavioral change(s) needed to improve health outcomes. The Theory of Planned Behavior will be the first of these theories reviewed.

THEORY OF PLANNED BEHAVIOR (TPB)

The Theory of Planned Behavior (TPB) is a framework for understanding, predicting, and changing human behavior. The Theory appears to have application in addressing nonadherent behavior in difficult populations. TBP is a general model that can be utilized when observing any behavior. Ajzen is the leading scholar in the field, and he and his colleagues point out:

> According to the theory, intention is the immediate antecedent of behavior and is itself a function of attitude toward behavior, subjective norm, and perceived behavioral control; and these determinants follow, respectively, from beliefs about the behavior’s likely consequences, about normative expectations of important others, and about the presence of factors that control behavioral performance. (Ajzen, 2012, p. 438)

Ajzen argues that thoughts and feelings lead up to decisions and therefore are helpful in explaining behavior, and that behaviors performed come from reasonable consideration of behavior-relevant information available to the individual.

TPB is a progression from the Theory of Reasoned Action (TRA) and adds the concept of the individual’s degree of control over behavior; TRA was limited to behaviors in which the individual had complete volitional control (Ajzen, 1985).

> People should be able to act on their intentions to the extent that they have the information, intelligence, skills, abilities, and other internal factors required to perform the behavior and to the extent that they can overcome any external obstacles that my interfere with behavioral performance. (Ajzen, 2012, p. 446)

Ajzen believes that people's intentions should be sufficient to predict behavior when control of behavior was high and that intention and control interact to affect performance of behavior.

> Attitudes toward the behavior, subjective norms with respect to the behavior, and perceived control over the behavior are usually found to predict behavioral intentions with a high degree of accuracy. In turn, these intentions, in combination with perceived behavioral control, can account for a considerable proportion of variance in behavior. (Ajzen, 1991, p. 206)

Therefore, intentions, subjective norm, and perceived behavioral control guide volitional human behavior. Ajzen (2012) defined perceived behavioral control as the extent to which an individual believes they can perform a specific behavior if they choose to do so, which he acknowledged as influenced by and congruent with Bandura's work around the concept of self-efficacy (1994). This concept of perceived behavioral control is interactive with the individual's intentions such that individuals who believe they can accomplish a given behavior will have higher intention to do so, and those uncertain of their capability to perform a given behavior will be unlikely to have intention to do so (Ajzen, 2012).

> Perceived behavioral control can thus influence behavioral performance indirectly by its effects of intentions to engage in the behavior and on perseverance in the face of difficulties encountered during execution. (Ajzen, 2012, p. 447)

Ajzen also believed that often in social sciences measures of actual control are not available and that perceived behavioral control can serve as a proxy and aid in the prediction of behavior. Individuals form perceived behavioral control from their beliefs about resources available, obstacles that may be present or arise, and their ability to perform.

> To summarize briefly, according to the TPB, human action is guided by three kinds of considerations: readily accessible beliefs about the likely outcomes of the behavior and the evaluations of the outcome (behavioral beliefs), readily accessible beliefs about the normative expectations and actions of important referents (normative beliefs), and readily accessible beliefs about the presence of factors that may facilitate or impede performance of the behavior and the perceived power of these factors (control beliefs). (Ajzen, 2012, p. 448)

Behavioral beliefs create an attitude toward a given behavior, normative beliefs are developed based on perceived social pressures, and behavioral control is a perception based on control beliefs.

> As a general rule, the more favorable the attitude and subjective norm, and the greater the perceived control, the stronger the person's intention to perform the behavior in question. (Ajzen, 2012, p. 448)

While TBP adheres to the idea that behavior is guided by beliefs and intentions, it does not assume that an individual's beliefs are rational, unbiased, or representative of reality.

> Beliefs reflect the information people have in the relation to the performance of a given behavior, but this information is often inaccurate and incomplete; it may rest on faulty or irrational premises, be biased by self-serving motives, or otherwise fail to reflect reality. (Ajzen, 2012, p. 451)

According to Ajzen (2012), the theory also acknowledges that individuals do not always review their beliefs prior to behavior and that many behaviors in daily life are done without much cognitive effort.

Ajzen et al. (2011) conducted four studies to evaluate the assumption that being well informed leads to effective action. Study 1 evaluated environmental knowledge and energy conservation; Study 2, alcohol knowledge and drinking behaviors; Study 3, attending a mosque service; and Study 4, evaluated voting to support Muslim student activities. Ajzen et al. agreed with DiClemente (1989) and Fisher and Fisher (1992), stating that "knowledge is a necessary but not a sufficient condition" (p. 115). Possessing knowledge or accurate information about a specific subject alone did not effectively direct or predict behavior.

> Attitudes, subjective norms, and perceptions of control were found to predict intentions to drink alcohol, to conserve energy, to attend a mosque service, and to vote support for Muslim student activities; these intentions were generally good predictors of the corresponding behavior. (Ajzen et al., 2011, p. 116)

While TPB itself does not attempt to theorize chronic illness, it does shed light on individual behaviors. With direct application to end-stage renal disease, TPB definitely highlights the demanded behavior changes of the individual in order to maximize his or her health and quality of life. Any behavior, such as medication compliance, that works to improve, maintain, or diminish one's health in relation to one's illness could be viewed through the lens of TPB. According to the Theory, an individual's beliefs and intentions guide behavior. Therefore, as healthcare professionals work with individuals regarding behaviors that need to be changed or modified, beliefs and intentions are important to discuss and consider for the greatest success in behavioral change. Information and education alone may not be sufficient for individuals to make needed changes in their routines and lives. TPB can prove useful in working with individuals to identify beliefs that may be hindering them from successful behavioral change. Perceived control of behavior, perceived obstacles, and beliefs about rewards or consequences of a given behavior can all be discussed, reviewed, supported, and/or challenged. The TPB supports that beliefs guide intentions, which in turn guide behavior. Therefore, healthcare professionals need not assume that the need to change behavior or the fear of declining health is sufficient for behavioral change.

TPB offers more in terms of describing an individual's cognition about behaviors than interventions that may be used. Healthcare professionals are left with a framework for understanding key components to behavioral change but no specific interventions to utilize. In their qualitative research with 36 people, Hwu and Yu (2006) found that "some participants identified behavioral belief as the most important factor. Once they believed that the adoption of a certain behavior (e.g., exercise, diet) would benefit their health status, they did so willingly" (p. 267).

The Theory of Planned Behavior aligns well with social work values and ethics. The individual is the expert on his life and situation. Only the individual can paint a picture of what he believes, feels capable of, considers obstacles, fears happening, is motivated to do, and his level of concern with social pressures or norms around a given behavior. Likewise, the goal of the healthcare professional is to empower clients to understand and describe their beliefs, overcome obstacles, acknowledge their strengths and networks, and assist them in the change process. Social workers advocate for clients regarding obstacles created by policies or the healthcare system and link clients to available resources that would aid in overcoming obstacles. In the next section, the Common-Sense Model (CSM) will be discussed as a useful theory in understanding illness representations and adherence behaviors.

COMMON-SENSE MODEL (CSM)

The Common-Sense Model (CSM) is another theory that focuses on behavior change in individuals with an illness. By understanding the "illness representations" that individuals generate, CSM has direct application to individuals with end-stage renal disease.

> The key construct within the CSM is the idea of illness representations or "lay" beliefs about the illness. These representations integrate with existing schemata (the normative guidelines that people hold), enabling them to make sense of their symptoms and guide any coping actions. (Hale, Treharne, & Kitas, 2007, p. 904)

The model focuses on how actions are guided by illness representations created from various sources of information available to the individuals. Leventhal, Bunyamini, and Brownlee (1997) detail five components of illness representation; they are *identity, cause, timeline, consequences,* and *curability/controllability.*

Illness representation is described as a label given to the illness/condition and symptoms and is created from available sources of information.

> The first source of information is the general pool of "lay" information already assimilated by the individual from previous social communication and cultural knowledge of the illness. The second source is information from the external social environment from perceived significant others or authoritative sources such as a doctor or patient. Finally, the individual completes her/his illness representation by taking into account their current experience with the illness. "Current experience" refers to the somatic or symptomatic information based on current perceptions and previous experiences with the illness. Current experience also encompasses knowledge of the effectiveness of previous means used to cope with the illness. (Hagger & Orbell, 2003, p. 142)

The interpretation of this information allows the individual to create a representation of their illness. These illness representations create coping responses and thus influence health outcomes (Leventhal, Meyer, & Nerenz, 1980).

The *cause* component of CSM is described as the individual's belief about what caused or contributed to their condition. For example, an individual may believe that stress at work is the reason they are experiencing headaches.

Timeline refers to the belief constructed by the individual as to how long the condition may last.

The *consequences* of the illness for a person's life refers to beliefs regarding the impact of the illness on overall quality of life or how it may affect functional capacity (e.g., "My illness prevents me [from] doing certain things.") (Hagger & Orbell, 2003, p. 143).

The *curability/controllability* component of CSM refers to the beliefs the individual holds regarding the value and effectiveness of treatment and management actions he might take, as well as his perceived ability to perform actions needed to manage his illness.

> The model proposes that the illness representation acts as a filter and interpretive schema for the available sources of information about the illness and how these guide action in response to the illness threat. Further, the model implies that the relationship is causal, that is, the illness cognition will exact an effect on coping behaviours in proportion with the perceived severity of the illness based on the representation derived from the stimuli. (Hagger & Orbell, 2003, p. 145)

Hagger and Orbell also stated that "viewing the illness as controllable was related to active coping variables such as problem-focused coping. In contrast, perceiving it as uncontrollable, chronic, and highly symptomatic was associated with avoidance and denial coping strategies" (p. 145). In an anecdotal fashion from my practice experience, individuals with end-stage renal disease feel that the majority of their illness is outside of their control.

In addition to the creation of illness representations, CSM is considered a "parallel processing model."

> According to CSM, information processing occurs on two parallel pathways. The cognitive pathway involves the creation of knowledge-based view or representation of the health problem and the development of a plan for coping with its objec-

> tive impact. The emotional pathway consists of emotional responses to a problem and the development of a coping plan for the management of emotional responses to the problem. (Barsevick, Whitmer, & Walker, 2001, p. 1364)

CSM acknowledges that both thoughts and emotions play a role when making decisions and carrying out behavior and that these two processes are taking place jointly.

In their meta-analysis of 45 empirical studies using CSM, Hagger and Orbell (2003) found that a moderate-to-strong relationship is present between illness cognitions, coping behaviors, and illness outcomes. Therefore, healthcare providers working with various individuals with illnesses should inquire about and evaluate the individual's perception of his illness. CSM offers clinicians key areas in which they can educate patients about their illness, challenge misinformation, encourage behaviors that aid in controlling symptoms and increasing a sense of well-being, and help them create an illness identity that is more accurate and appears more manageable.

Ward et al. (2009) developed an approach using the Common-Sense Model with cardiac patients to evaluate patients and shape concepts. This model includes a formal assessment of pain representations, discovering and addressing misconceptions, provision of information to correct misconceptions, and summarizing the discussion. This approach allows for both the patient's input and description of his illness, and the healthcare provider's sharing of knowledge and clarification of symptoms and the illness, instead of simply issuing a treatment regimen.

In their study of 79 women receiving treatment for breast cancer, Costanzo, Lutgendorf, and Roeder (2011) found that:

> Women who believed their cancer had more severe consequences and those who attributed the development of cancer or the prevention of recurrence to health behaviors or stress were most likely to report improvement in diet or physical activity and reduction in alcohol use or stress. (p. 53)

Paddison, Alpass, and Stephens (2010) used the Common-Sense Model to understand diabetes-related stress and found that "people who report that their diabetes is puzzling and difficult to make sense of are more likely to experience higher distress about diabetes" (p. 47). Paddison et al. (2010) also noted that high stress related to diabetes created difficulty in the development of accurate perceptions about the illness. "In this study, general mental health and self-reported depression together explained 14% of differences in distress about diabetes. However, illness perceptions accounted for a further 15% of differences in diabetes-related distress" (Paddison et al., 2010, p. 48). Individual beliefs about illness directly impact health outcomes and the Common-Sense Model concretely offers insight into understanding these illness representations. Next, improving behavioral change through the lens of Motivational Interviewing (MI) will be discoursed.

MOTIVATIONAL INTERVIEWING (MI)

Another theoretical approach utilized in research and practice to improve behavioral outcomes is Motivational Interviewing (MI). MI, while attending to the nonaherence variable in populations with end-stage renal disease, offers important elements for practice. Miller and Rollnick (1991) described five stages when considering behavior change in an individual. These stages are *pre-contemplation*, *contemplation*, *preparation*, *action*, *maintenance*, and *relapse*. *Pre-contemplation* is the time in which the individual is unaware of the need to make changes, or unwilling to make changes. Once the individual begins to consider the notion of change, he is in the con*templation* stage. When the individual has decided that making changes is something he has desire to do and the intention to change is present, he is in the *preparation* stage. The *action* stage begins when the individual starts and continues to carry out actions or behaviors that are capable of creating change. Upon successfully progressing toward or achieving behavior change, the individual must *maintain* new behavior with consistent actions and possibly lifestyle modifications. And finally, *relapse* can occur at any point in the process and is considered a return to previous behaviors or cessation of more productive behaviors.

Along with describing the process of change, Miller and Rollnick (1991) address the need to motivate individuals to make changes. MI is a "psychological approach that aims to increase motivation to engage in treatment or a direct, client-centered counseling style for eliciting behavior change by helping patients to explore and resolve ambivalence" (Karalis & Wiesen, 2007, p. 336). Using acceptance and reflective listening, the healthcare provider expresses empathy toward the patient regarding behaviors that may be difficult to change or adopt and assists the patient in identifying non-congruence with behaviors and goals (Russell et al., 2011). Using an example of medication compliance, Russell et al. (2011) provide an example of working with a patient:

> Readiness to change should also be assessed using the Importance and Ability Ruler. The provider asks "On a scale of 1 to 10, with 1 being not ready at all, and a 10 being very ready, how ready are you to make changes so that you take your medications on time every day?" When the patient responds with a number (for example, with a 6), the provider asks "Why did you choose a 6 and not a 3 (some lower number)?" When the patient provides a rationale, the provider asks, "What would it take for you to feel like you could get from a 6 to an 8?" (p. 230)

The goal of the healthcare provider is to elicit positive discussions and to encourage and support talk of change. Karalis et al. (2007) suggest four activities for the clinician that can positively influence interactions with clients: *ask non-judgmental, open-ended questions*; *listen carefully*; *set goals with the patient and not for the patient*; and *involve the patient in problem solving* (p. 336–337). These four activities help to build rapport with the patient and also recognize that it is essential for the individual to be involved in the process.

Using a convenience sample of 29 patients, Russell et al. (2011) studied the use of MI for improving adherence with hemodialysis patients. The authors found that dialysis attendance, shortened treatments, and phosphorus and albumin levels were favorably influenced by MI, though the findings were not statistically significant (Russell et al., 2011). This pilot study showed promise; however, the authors recommend future studies using a randomized controlled trial design. In a systematic review of literature, Hill and Kavookjian (2012) found that the use of Motivational Interviewing was also successful in improving health outcomes and adherence in HIV-positive patients.

DISCUSSION

The Theory of Planned Behavior (TPB), the Common Sense Model (CSM), and Motivational Interviewing (MI) all provide insight into behavioral change. Several commonalities exist: listening to the individual, addressing misconceptions, educating with accurate information, understanding what the individual is willing to do, and encouraging and supporting the individual's change efforts. Ultimately, all three theories are attempting to address the same issue (behavioral change), while providing slightly different insights into the process of change in individuals. Though the insights are different, they also are compatible and dovetail to provide a larger and more in-depth view of individuals facing the need to change behaviors. Each theory also reminds and informs us that knowledge alone is not sufficient to bring about changes in behavior.

While TPB and the CSM do not offer any specific interventions, they do provide a framework for understanding the process individuals are going through and provide social workers with key concepts to explore and to potentially challenge. MI offers a more structured approach for exploring an individual's current status and willingness to make changes in behavior and focuses on encouraging the individual and motivating him to find and make the changes he is willing to do. All three theories acknowledge that change is governed by internal processes in the person. The social worker's job is to explore those internal processes with the person using empathy and non-judgmental questioning. By building rapport with the person, the social worker can challenge misconceptions and non-congruent behaviors, and support change efforts. While all three theories are congruent with social work values and ethics, two values and ethical principles are exemplified in these approaches. These are: *dignity and worth of the person* and *importance of human relationships*. The National Association of Social Workers (NASW) outlines the value the *dignity and worth of the person* as:

> Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients' socially responsible self-determination. Social workers seek to enhance clients' capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients' interests and the broader society's interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession. (NASW, 2012)

And *importance of human relationships* as:

> Social workers understand that relationships between and among people are an important vehicle for change. Social workers engage people as partners in the helping process. Social workers seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain, and enhance the well-being of individuals, families, social groups, organizations, and communities. (NASW, 2012)

These values should always be guiding the social worker's practice with people and lay the foundation for successful work. Upon that foundation, theories like the Theory of Planned Behavior, Common-Sense Model, and Motivational Interviewing can be used to assist individuals in the pursuit of maximized health outcomes.

REFERENCES

Ajzen, I. (1985). From intentions to actions: A theory of planned behavior. In J. Kuhi & J. Beckman (Eds.), *Action—control: From cognition to behavior* (pp. 11–39). Heidelberg: Springer.

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*, 179–211.

Ajzen, I. (2012). The theory of planned behavior. In P.A.M., Van Lange, Kruglanski, A.W., & Higgins, E.T. (Eds.), *Handbook of theories of social psychology (Vol 1)* (pp. 438–459). Thousand Oaks, CA: Sage Publications.

Ajzen, I., Joyce, N., Sheikh, S., & Cote, N. G. (2011). Knowledge and the prediction of behavior: The role of information accuracy in the theory of planned behavior. *Basic and Applied Social Psychology*, *33*, 101–117. doi:10.1080/01973533.2011.568834

Bandura, A. (1994). *Self-efficacy.* New York: John Wiley & Sons, Inc.

Barsevick, A. M., Whitmer, K., & Walker, L. (2001). In their own words: Using the Common Sense Model to analyze patient descriptions of cancer-related fatigue. *Oncology Nursing Forum*, *28*(9), 1363–1369.

Costanzo, E. S., Lutgendorf, S. K., & Roeder, S. L. (2011). Common-sense beliefs about cancer and health practices among women completing treatment for breast cancer. *Psycho-Oncology*, *20*, 53–61.

DiClemente, R. J. (1989). Prevention of human immunodeficiency virus infection among adolescents: The interplay of health education and public policy in the development and implementation of school-based AIDS education programs. *AIDS Education and Prevention*, *1*, 70–78.

Engle, R. J., & Schutt, R. K. (2009). Fundamentals of social work research. Los Angeles: Sage Publications, Inc.

Fisher, J. D., & Fisher, W. A. (1992). Changing AIDS-risk behavior. *Psychological Bulletin*, *111*, 455–474.

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representation. *Psychology and Health*, *18*(2), 141–184.

Hale, E. D., Treharne, G. J. & Kitas, G. D. (2007). The common-sense model of self-regulation of health and illness: How can we use it to understand and respond to our patients' needs? *Rheumatology*, *46*, 904–906.

Hill, S., & Kavookjian, J. (2012). Motivational interviewing as a behavioral intervention to increase HAART adherence in patients who are HIV-positive: A systematic review of literature. *AIDS Care*, *24*(5), 583–592. doi:10.1080/09540121.2011.630354

Hwu, Y. & Yu, C. (2006). Exploring health behavior determinants for people with chronic illness using the constructs of planned behavior theory. *Journal of Nursing Research*, *14*(4), 261–269.

Karalis, M., Wiesen, K., & Brommage, D. (2007). Issues in renal nutrition. Motivational interviewing. *Nephrology Nursing Journal, 34*(3), 336–338.

Leventhal, H., Benyamini, Y., & Brownlee (1997). Illness representations: Theoretical foundations. In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness* (pp. 19–45). Amsterdam: Harwood Academic.

Leventhal, H., Meyer, D., & Nerenz, D. R. (1980). The Common Sense representation of illness danger. In S. Rachman (Ed.), *Contributions to medical psychology, Vol. 2* (pp. 17–30). New York: Pergamon Press.

McCarley, P. (2009). Patient empowerment and Motivational Interviewing: Engaging patients to self-manage their own care. *Nephrology Nursing Journal*, *36*(4), 400–413.

Miller, W. R. & Rollnick, S. (1991). Motivational Interviewing: Preparing people to change addictive behavior. New York: Guilford Press.

National Association of Social Workers (NASW). (2012). Code of ethics. Retrieved from http://www.socialworkers.org/pubs/code/code.asp

Paddison, C. A. M., Alpass, F. M., & Stephens, C. V. (2010). Using the Common Sense Model of illness self-regulation to understand diabetes-related distress: The importance of being able to "make sense" of diabetes. *New Zealand Journal of Psychology*, *39*(1), 45–50.

Russell, C. L., Knowles, N., Peace, L., Cronk, N. J., Matteson, M. L., Ponferrada, L., & Herron, M. (2011). Motivational Interviewing in Dialysis Adherence Study (MIDAS). *Nephrology Nursing Journal, 38*(3), 229–236.

Ward, S. E., Serlin, R. C., Donovan, H. S., Ameringer, S. W., Hughes, S., Peromashko, K., & Wang, K. (2009). A randomized trial of a representational intervention for cancer pain: Does targeting the dyad make a difference? *Health Psychology*, *28*, 588–597.

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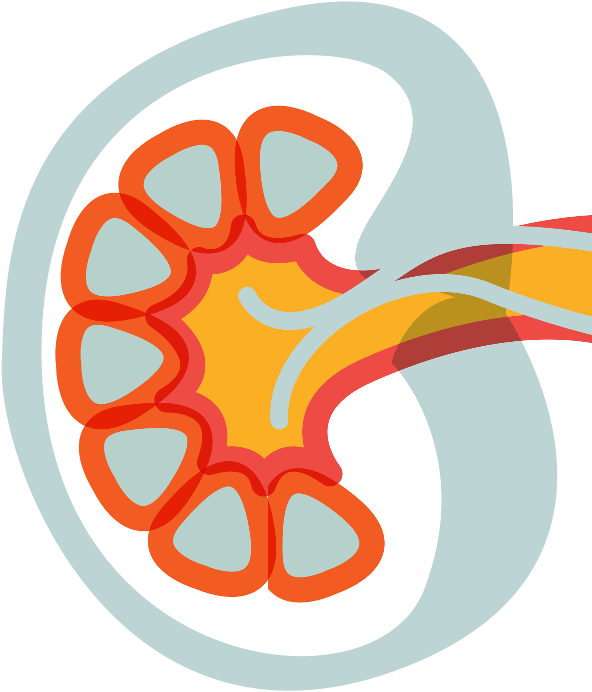

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