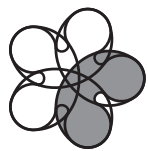


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als working in the field of renal social work.

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

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- Text
- References
- Appendixes
- Author note
- Footnotes
- Tables
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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). Religious 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.

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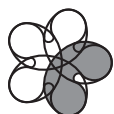
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Let's Talk About Sex: Understanding Social Workers' Approaches to Discussing Sexuality With CKD Patients

*Julie Burnett, MSW, RSW; Amy Canter, MSW, RSW; Melissa Rubin, MSW, RSW;
Michelle Verdirame, MSW, RSW; Canadian Association of Nephrology Social Workers, Toronto, Canada*

A review of the literature suggests that patients do not typically initiate conversations related to sexual function. Our small exploratory pilot study set out to understand the barriers social workers face when initiating discussion of this quality-of-life issue. Forty-two members of the Canadian Association of Nephrology Social Workers responded online to a short survey pertaining to their discussions with CKD patients around sexual function. The majority of respondents felt they had a working knowledge of CKD and sexual function. Despite most reporting some knowledge and comfort in discussing the issue, only half said they initiate the discussion. This article describes barriers to the discussion of sexual function and presents implications for social work practice.

INTRODUCTION

The nature of chronic kidney disease (CKD) strongly influences sexual function (Rozenman et al., 1990). The literature suggests that sexual function is compromised among both male and female patients with CKD (Arslan et al., 2002; Hickman, 1977; Katz, 2006; Peng et al., 2005; Steele et al., 1996). CKD also plays a significant role in the lack of development of sexual function in men and women (Turk et al., 2001). Physical and psychological factors impact patients' sexual function. Physical factors include pain, fatigue, hormone imbalance, uremia, anemia, leg cramps, medications and other medical issues (Arslan et al., 2002; Hart & Thomas, 2007; Katz, 2006). Psychological factors include anxiety, depression, sleep disorders, body image and change of role or identity within the family (Arslan et al., 2002; Hart & Thomas, 2007; Katz, 2006). In terms of sexual complaints, men report a high incidence of erectile dysfunction, reduced libido, lack of desire and orgasm complaint (Arslan et al., 2002; Katz, 2006). Women report reduced libido and lubrication, orgasm complaints, pain during intercourse and lack of pleasure (Katz, 2006).

Some studies suggest the different types of dialysis (e.g., hemodialysis vs. peritoneal vs. nocturnal) do not play a role in the degree of sexual dysfunction a patient may have (Katz, 2006; Steele et al., 1996). Another study found that of 249 women aged 23–65 with CKD, hemodialysis patients had a five times greater risk of having sexual function problems than peritoneal dialysis patients (Kettas et al., 2008).

It appears that patients on dialysis have more sexual difficulties than patients who are pre-dialysis or who have been transplanted (Katz, 2006; Steele et al., 1996). The prevalence of sexual function problems is estimated to run between 9% in pre-dialysis patients and 60–70% in men and women who are already on dialysis (Kettas et al., 2008). Several studies suggest that there is a significant link between sexual function and perceived quality of life for renal patients (Arslan et al., 2002; Hart et al., 1995; Ho & Fernandez, 2006; Steele et al., 1996). One study of 578 female patients on hemodialysis reported that the women with higher Index of Female Sexual Function ratings had significantly higher scores in physical functioning and mental health (Peng et al., 2005). Another study suggested that a lack of sexual activity is an important

determinant in a patient's self-assessment of quality of life (Steele et al., 1996).

In terms of the health care provider's role in disseminating information about sexual function, one study of successful transplant survivors showed that 70% of those interviewed said they wanted their health team to provide information on sexual function as it relates to CKD. However, only one-third of patients received this information (Hart et al., 1995). It is important to note that patients perceive their sexual health as important and worthy of attention (Ho & Fernandez, 2006). Of particular interest is the finding in one study that stated that the level of acceptance of patients' illness relates to their level of sexual function and satisfaction (Alleyne et al., 1989).

Research shows a pervasive tendency on the part of the nephrology health care team to avoid addressing the sexual function issue with renal patients (Arslan et al., 2002; Ho & Fernandez, 2006). To complicate matters further, the same tendency exists amongst the patients themselves (Arslan et al., 2002). Chronically ill patients, even those with a high level of awareness of their sexual function, rarely refer themselves to professionals for help (Hart et al., 1995). This reluctance to seek help places the responsibility on the health professional to initiate discussions around sexual function. Several studies suggest multiple reasons why health care professionals do not discuss sexual function with their patients (Arslan et al., 2002; Hart et al., 1995; Steele et al., 1996; Ho & Fernandez, 2006). These reasons include the belief that an in-depth understanding of sexual function and treatment methods is unnecessary (Hart et al., 1995), a lack of basic education about this subject as well as cultural, personal and religious factors (Hart & Thomas, 2007; Ho & Fernandez, 2006).

METHODS

The Canadian Association of Nephrology Social Workers (CANSW) is a national association comprised of 114 members from across Canada who hold either a bachelor's or master's degree in social work (or both) and provide social work services to CKD patients in a variety of settings. They are appropriately licensed or registered in accordance with the province or territory in which they reside.

Following the 2006 CANSW National Conference in Ottawa, Ontario, the organization developed a small working committee to address psychosocial issues facing renal patients and their families. The committee developed the following questions to be studied: How do CANSW members view their role with regard to discussing sexual function with renal patients? What are their current practices for doing so?

The committee completed a small-scale exploratory pilot study using a sample of CANSW members. There were 42 respondents: 37 females and 5 males. (At the time, there were 100 female and 12 male CANSW members.) The respondents' mean age was 46.4 years with a range of 27–65 years. As CANSW does not keep age data, it was not possible to know the ages of all potential respondents. Respondents varied in years of nephrology social work practice from 0.25 to 24 years. The years of nephrology social work experience was an average of 9.2 years among respondents, compared with 6.3 years among CANSW's general membership. The patient population areas served by the respondents varied and reflected the major areas of nephrology, including predialysis, peritoneal dialysis, hemodialysis and transplant. The majority of respondents (77%) worked within multiple nephrology populations, which is also true of the entire membership.

We used an online software program (<http://www.surveymonkey.com>) to design a 16-question survey to investigate CANSW members' views regarding their role in discussing sexual function with people with end-stage renal disease (see Appendix A). The questions were both open- and closed-ended, allowing respondents to check appropriate answers provided or offer their own explanations. Descriptive scales were employed to allow respondents to rate themselves on specific variables related to discussing sexual function, including comfort, knowledge and barriers to communication (e.g., "very," "somewhat," "not at all").

RESULTS

Research Question 1: How do CANSW members view their role with regard to discussing sexual function with renal patients?

Social workers were asked if they felt it was their role to discuss sexuality with their patients. All 42 participants indicated that it was their role, and the majority (92.9%) felt it was their role in collaboration with other health care professionals including the nephrologist, nurse and sexuality consultant, as available.

Research Question 2: What are CANSW members' current practices for discussing sexual function with renal patients?

Respondents were asked if they initiated discussions regarding sexuality with their CKD patients. Slightly more than half (52.4%) said that they initiate this discussion with their patients. Of those respondents that initiate these discussions, 44.4% of those do so "occasionally." Zero respondents indicated they do so routinely.

Table 1 highlights a number of reasons why nephrology social workers do not initiate discussions around sexuality, including lack of knowledge, privacy, personal discomfort, perception of patient's discomfort and privacy concerns.

Table 1

Reasons Why Nephrology Social Workers Do Not Initiate Discussions Around Sexuality With CKD Patients (n = 65)

Reasons	Number of Respondents	Percent (%)
Lack of privacy	18	42.8
My discomfort	9	21.4
My perception of their discomfort	13	30.9
Lack of knowledge on my part	13	30.9
Other	12	28.5
Total no. of responses	65	

In terms of their knowledge and comfort level, while 9.5% (4) of respondents felt they had "a lot of knowledge," the greatest majority of respondents at 50% (21) reported that they had a "working knowledge" of CKD and sexuality. Three respondents (7.1%) indicated that they did not have any knowledge at all.

With regard to comfort level, the majority of social workers felt "somewhat comfortable" (31.7%; 13) and "fairly comfortable" (31.7%; 13) when it came to discussing the issue of sexuality with their CKD patients, while 4.9% (2) of respondents felt "not comfortable." One individual skipped this question.

In addition to knowledge and comfort level, several participants disclosed more than one reason why they don't talk about sexual function. Table 2 highlights the more common responses, which were categorized into themes based on the 11 additional "other" reasons. For instance, more than 50% indicated that they do not initiate discussions with their CKD patients around sexual function because their expectation is that the patient would bring up the issue if they felt it was important. They did not want to make the patient uncomfortable by bringing the issue up themselves.

Additional reasons included time constraints and having other priorities. One participant indicated that the nurse, who sees patients first in the nephrology clinic, initiated such discussions. Another respondent stated the nephrologists in that program didn't believe it was an important issue to discuss.

Table 2

Other Reasons Why Nephrology Social Workers Do Not Initiate Discussions Around Sexuality With Their CKD Patients (n = 12)

Reasons	Number of Respondents	Percent (%)
Lack of time	1	8.3
Other psychosocial issues take priority (e.g., financial concerns)	1	8.3
Patients do not identify it as an issue	6	50.0
Perception that it is not an issue for the particular population of patients respondent served (e.g., senior patients)	2	16.7
Topic addressed by other colleagues	2	16.7
Total no. of responses	12	

DISCUSSION

Given that there is a strong link between sexual function and renal disease (Rozenman et al., 1990) and that sexual health is significantly linked to quality of life (Steele et al., 1996), it is important to address concerns about sexual function with CKD patients both in their clinical assessments and treatment plans.

Our study showed a high percentage (47.6%) of nephrology social workers do not initiate discussions around sexual function with their patients. Reasons cited include lack of privacy, lack of knowledge, perceived discomfort and sexual function not being a topic raised by patients themselves. They felt it was often overlooked because of other pressing psychosocial issues and/or lack of resources and tools. Respondents were pleased that the issue is being addressed by CANSW and believed sexual function was a significant, worthy topic. The committee advised potential respondents that results would be considered to develop policies and guidelines for discussing sexuality with the CKD patient and a great majority (97.6%) felt that it would be helpful to have such policies/guidelines.

Half of the respondents had tools to help initiate discussions related to sexuality. The list of those resources and tools included medical literature, National Kidney Foundation literature (from both the United States and Canada) and Internet resources. Other disease-specific groups (e.g., cardiac, stroke and oncology) have also designed tools and strategies for coping with this patient care area. We can learn from these other professionals.

When is the best time to discuss this topic with patients? One suggestion was that sexual function be addressed in the pre-dialysis clinic. That way, patients can be made aware that sexual function may be a common concern for people with CKD and that the team is available to address any concerns they may have. Many pre-dialysis clinics were said to give patients a questionnaire to complete before their initial visit. It was suggested that sexual function be addressed in this questionnaire so that the nephrology team can be made aware of any issues from the beginning. In this way, the issue can be normalized early in the care process.

Respondents were asked for ideas on how to address this issue to allow for increased understanding and discussion with patients. Because many renal units have newsletters, one suggestion was to include information about sexual function in them. Another suggestion was to develop a questionnaire that included the questions about sexual function. Patients could answer as they wish and a private, individualized session could be arranged.

The busy environment of the hemodialysis unit, where 10–15 patients sit together and are dialyzed in one room, plays an obvious role discussing this sensitive subject. It would be interesting to compare how the issue is managed with peritoneal dialysis patients, who have individual clinic appointments versus hemodialysis patients where the next patient is often only an arm's reach away. On the other hand, renal social workers do discuss other sensitive subjects in the busy hemodialysis unit, such as advance directives and end-of-life care. There appears to be something more acceptable about discussing death than there is about discussing sexual function.

The study indicates that 92.6% of respondents felt that the discussion of sexual function with a patient is a social work role in collaboration with other team members, including the doctor, nurse and pharmacist. Each team member brings his/her specific expertise to the subject. Something this study did not touch upon is the perspective of patients' partners. Social workers are well-equipped to deal with intimacy and closeness issues that are so entwined with sexual function. Social workers can also take the role of providing education to other team members about the prevalence of problems with sexual function in CKD patients and the need for sensitivity.

Of the respondents surveyed, many indicated that they would like to use educational materials for encouraging discussion. They also look to other team members for guidance and support. Providing the means for private discussions and increasing knowledge, comfort level and access to tools for discussing sexual function is essential for these conversations with patients to take place.

We suggest that our attention as social workers needs to be directed toward increasing opportunities, comfort and knowledge around the topic of sexual function not only for patients, but also for ourselves as clinicians. As social workers, we often tackle harsh human realities. We need to view

the topic of sexual function and CKD patients as a routine aspect of our social work assessment.

LIMITATIONS

There are a few limitations to this study that need to be highlighted. First, while a significant topic, a dearth of research exists around CKD and sexuality, which made it difficult to provide a comprehensive literature review. Second, with a response rate of 37%, the small sample does not accurately represent CANSW as a whole population. Finally, the survey tool, designed by the researchers, was not tested for reliability or validity.

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Appendix A

CKD and Sexuality Survey

INTRODUCTION

The purpose of this survey is to determine current CANSW member practices when it comes to talking to our patients about chronic kidney disease (CKD) and sexuality. Your identity and answers will remain anonymous and confidential. Information received from the completion of this survey will be used to develop a protocol for CANSW members to use in future discussions with patients about CKD and sexuality.

1. Gender:

- Male Female

2. Age: _____

3. Number of years in nephrology social work: _____

4. Population served: (Check all that apply.)

- Pre-dialysis
 PD
 HD
 Home hemodialysis
 Transplant

5. Please rate the following:

How knowledgeable do you feel about CKD and sexuality?

- No knowledge Some knowledge Working knowledge A lot of knowledge Expert knowledge

6. Please rate the following:

How comfortable do you feel talking to your patients about CKD and sexuality?

- Not comfortable Somewhat comfortable Fairly comfortable Comfortable Very comfortable

7. Do you initiate a discussion with your patients about sexuality?

- Yes No

8. If yes ...

How often do you talk about it with them?

- Seldom Occasionally Frequently With every patient N/A

9. If no ...

Why don't you talk about it with them?

- Lack of privacy
 My discomfort
 My perception of their discomfort
 Lack of knowledge on my part
 Other (please specify)

10. What might help you to address the topic of sexuality with your patients?

11. Do you feel it's your role to talk about sexuality with your patients?

- Yes, it's my role
- It's my role in part, with collaboration from other professionals
- No, it's not my role at all

12. If not, whose role is it?

- Nephrologist
- Nurse
- Sexuality consultant
- Other (please specify)

13. This survey will be used to help develop some guidelines for CANSW members to follow when discussing sexuality with their patients. Would you find these guidelines helpful?

- Yes
- No

14. In the past, have you used any resources or tools for discussing sexuality with your patients?

- Yes
- No

15. If you have, what resources or tools have you used to discuss sexuality with your patients?

16. Do you have any additional comments/suggestions as to how this subject should be or could be addressed by nephrology social workers?

Renal Replacement Therapy and Barriers to Choice: Using a Mixed Methods Approach to Explore the Patient's Perspective

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Alternatives to in-center hemodialysis as treatment for end-stage renal disease have been shown to increase patient quality of life, decrease co-morbidities and decrease financial strain on both the patient and the health care system. Focus groups (n = 6 groups with 47 participants) and survey data (n = 113) were used to ascertain perceived barriers and facilitators to alternative therapies and psychosocial and educational issues that may affect a patients' choice of modality among patients utilizing in-center dialysis, home dialysis and renal transplantation. Fear emerged as a predominant theme, both at diagnosis and when choosing a modality. Distrust of the medical system, denial and patient experiences with previous modalities were seen as barriers to care. Results imply that interventions addressing fear and providing more comprehensive pre-dialysis education may decrease barriers.

INTRODUCTION

The incidence and prevalence of end-stage renal disease (ESRD) in the United States continues to rise, creating a mounting burden on patients, caregivers and the medical system (United States Renal Data System [USRDS], 2008). Although peritoneal dialysis (PD), home hemodialysis (HD) and kidney transplantation have been shown to increase patient independence, decrease co-morbidities and increase patient quality of life overall, rates of these alternative renal replacement therapies (RRTs) remain low (Arkouche et al., 1999; Medical Education Institute, 2006; Mehrotra, Marsh, Vonesh, Peters, & Nissenson, 2005; Rubin, Fink, Plantiga, Sadler, Klinger, & Powe, 2004; USRDS, 2008; Wu et al., 2001). Rates of PD peaked in 1995 at 15% but have tapered off since then. According to 2006 prevalence data from the USRDS (2008), only 5.2% of ESRD patients are on PD, less than 2.6% are treated with home HD and only 30% have a working kidney transplant. Economically speaking, switching to or starting home therapies or receiving a kidney transplant is less expensive for both the patient and the medical system, with HD costs at \$71,889 per person per year in 2006, compared to \$53,327 and \$24,951 for PD and transplant, respectively (Shih, Guo, Just, & Mujais, 2005; USRDS, 2008).

In the face of dramatic developments in treatment and technology and increasing patient-centered education, research has begun to focus on potential reasons for patients' reluctance to choose an alternative to in-center HD. Pre-dialysis educational programs have been shown to decrease anxiety about dialysis and have a positive effect on participants' feelings that they have the knowledge and tools to make their own choice about RRT, but these programs are not mandated and are often infrequent (Goovarts, Jadoul, & Goffin, 2005; Iacono, 2005; Klang, Bjorvell, & Cline, 1999; McLaughlin, Manns, Mortis, Hons, & Taub, 2003; Mehrotra et al., 2005). Myths abound in both patient and provider communities about PD, including perceptions that it is inappropriate for patients who are noncompliant or obese, has poor survival rates, has high infection risks, and demands that patients be totally independent (Bernardini, 2004).

Focused interviews and surveys among ESRD patients have started to explore issues of choice regarding RRT (Bernardini, 2004; Landraneau & Ward-Smith, 2006; McLaughlin et al., 2003; Tweed & Ceaser, 2005; Winkelmayr, Glynn, Levin, Owen, & Avorn, 2001; Wuerth et al., 2002). Focus groups and interviews have previously addressed patient satisfaction and quality-of-life domains (Bass et al., 1999; Rubin et al., 2004; Wu et al., 2001). PD patients gave significantly higher ratings on items such as "information given to help choose modality" and "the amount of dialysis information from staff" as compared with HD patients (Rubin et al., 2004). There were also statistically significant differences between PD and HD with regard to amount of travel required, dietary restrictions, sleep, role functioning and general quality of life, all favoring PD (Bass et al., 1999; Rubin et al., 2004).

There has been considerable research on modality choice and quality of life for ESRD patients but less is known about how patients are presented with the information, how patients may receive it based on psychosocial factors and what patients are going through physically and emotionally at the time RRT information is presented. Focus groups and survey data were used for an exploratory analysis with ESRD patients to better understand their perceptions of methods for educating newly diagnosed ESRD patients about RRT; perceptions of their disease at onset and how these perceptions may influence their choice of RRT; and perceived barriers and facilitators to alternative forms of RRT.

METHODS

This project utilized a "mixed model" approach, employing both qualitative (focus group) and quantitative (survey) data within and across the stages of the research process. This approach allows the researcher to draw from the strengths and minimize the weaknesses in both quantitative and qualitative methodologies (Johnson & Onwuegbuzie, 2004). The mixed model can be viewed as a third, hybrid paradigm of research methodology, and is useful for measuring different and overlapping facets of the same research question using different research approaches (Greene, Caracelli, & Graham, 1989; Tashakkori & Teddle, 2002).

Study Sample and Recruitment

Recruitment for focus groups was performed by nephrology social workers at two dialysis clinics in North Carolina. Eligible participants were English-speaking patients on in-center and home dialysis therapies (PD or home HD) who were 18 or older. Patients eligible for home dialysis therapies who instead chose in-center HD were eligible for the in-center HD groups. Separate groups for home dialysis patients were utilized to explore the factors that made these groups more likely to choose home therapy over in-center dialysis. Participants signed consent at the time of the focus group and received a \$25.00 gift card as reimbursement for time and travel.

Subjects for survey participation were recruited by nephrology social workers through five dialysis clinics in North Carolina and by one of the researchers at the kidney transplantation clinic of UNC Hospitals, which sees approximately 100 patients every month. Surveys were self-administered and completed in the clinic or at the dialysis unit. Eligible participants were English-speaking in-center or home dialysis (HD or PD) patients or kidney transplant recipients who were 18 or older. There was no reimbursement for survey participation. Eligible patients were given an informed consent explaining the study and efforts to protect patient confidentiality.

Approval by the University of North Carolina Institutional Review Board was obtained prior to the implementation of the study.

Design: Focus Groups

Focus groups were conducted between August and September 2007. The lead investigator moderated all groups. The moderator used a scripted discussion guide that was created by the study investigators. Each focus group session lasted between 60 and 90 minutes, and was audiotaped and transcribed verbatim. Questions for discussion were framed under two main themes: (a) patient experiences dealing with disease onset and RRT modalities and (b) choosing a modality. Appendix A lists the questions used in the focus groups, along with corresponding “probe” questions to keep the discussion going.

Individual recordings were transcribed and uploaded into ATLAS.ti software package (Muhr, 2005). ATLAS.ti allows researchers to more easily code, organize and interpret qualitative data. Researchers utilized the grounded theory approach, which allows the theory to emerge from the data, versus a hypothesis-driven theory (Glaser & Strauss, 1967). Grounded theory uses open coding (free form coding for words, themes, expressions, etc.) followed by axial coding, which seeks to explore categories created through the open coding process. Because this was an exploratory study, the authors utilized grounded theory to let the data “speak for itself” with the use of ATLAS.ti to supplement coding procedures and data organization.

The first and second authors used open coding to create a “base coder list” devised from their individual readings of the

transcripts. All transcripts were then re-reviewed and coded by the same two members of the research team. Themes emerged in each section based on ongoing analysis using axial coding. Codes present in three or more theme sections were investigated by extracting those codes from the whole transcript and then examining codes that co-occurred within each theme section. Co-occurring codes within theme sections were reviewed and discussed by the same two co-authors for consistency and to increase inter-rater reliability. The authors were satisfied that saturation had been reached.

Design: Survey

Surveys were collected to gather quantitative data on a broader ESRD population outside the focus groups. Survey questions captured demographic data, awareness of dialysis options, pre-dialysis educational opportunities and reasons for and against alternative modality choices. The survey was developed by the co-authors, based, in part, on literature review, with consensus agreement on items to include. The survey was not validated prior to its employment.

All survey participants answered general demographics questions (education, income, insurance status, etc.), described factors around the time of their ESRD diagnosis (acute vs. chronic renal failure, length of time seen by nephrologists before renal failure) and gave their perceptions on the quantity and quality of RRT education. The remaining survey questions were divided into sections based on modality (in-center HD, home dialysis or transplant) and addressed perceived barriers to other forms of dialysis and factors influencing how they made the choice for their current modality.

Survey responses were analyzed using Stata 10.1 (StataCorp, 2007). Tabulated proportions and means were determined by complete case analysis. Continuous variables among categories of RRT were compared using one-way analysis of variance (ANOVA) if normally distributed. Kruskal-Wallis testing was employed for continuous variables not distributed normally. Categorical variables were compared using Fisher’s exact test. Test statistics producing $p < 0.05$ were considered to be statistically significant.

RESULTS

Focus Group Demographics

A total of 47 patients participated in 6 focus groups (Table 1). There were 12 participants on PD and 35 receiving in-center HD; no home HD patients participated. One transplant patient participated in a PD group. Four participants did not report age. One of these four also did not report education level or insurance status, and another did not report number of years on dialysis. There was an overrepresentation of female and African-American participants that was somewhat greater in the HD group, which was 70% female and 80% African American, compared to the PD group, which was 60% female and 60% African American. These differences, however, did not achieve statistical significance.

Table 1*Focus Group Participant Characteristics*

	In-Center Hemodialysis (N = 35)	Peritoneal Dialysis (N = 12)	p-Value	Total (N = 47)
Age, years (SD), (N = 43)	54.6 (12.9)	49.3 (16.3)	0.3	53.1 (13.9)
Sex (%), (N = 46)			0.5	
Male	10 (29.4)	5 (41.7)		15 (32.6)
Female	24 (70.6)	7 (58.3)		31 (67.4)
Race (%)			0.2	
White				
African American	6 (17.1)	5 (41.7)		11 (23.4)
Hispanic	28 (80.0)	7 (58.3)		35 (74.5)
	1 (2.9)	0		1 (2.1)
Education (%), (N = 46)			0.8	
Did not graduate high school	9 (26.5)	2 (16.7)		11 (23.9)
High school graduate	10 (29.4)	5 (41.7)		15 (32.6)
> High school education *	15 (44.1)	5 (41.7)		20 (43.5)
Years on dialysis, median (IQR)[†], (N = 46)	4 (2, 7)	1 (1, 3)	0.005	3 (1,6)
Insurance status (%), (N = 46)			0.1	
Medicare	10 (29.4)	2 (16.7)		12 (26.1)
Medicare/Medicaid	13 (38.2)	2 (16.7)		15 (32.6)
Medicare/Private ins.	8 (23.5)	6 (50.0)		14 (30.4)
Medicare/State plan	2 (5.9)	0		2 (4.4)
Other	1 (2.9)	2 (16.7)		3 (6.5)
On transplant wait list (%)			0.8	
Don't know	18 (51.4)	8 (66.7)		26 (55.3)
	3 (8.6)	1 (8.3)		4 (8.5)
Previously on other modality (%)	10 (28.6)	10 (83.3)	0.002	20 (42.6)

*Includes those who attended vocational/technical schools, college (whether or not completed) and those with graduate/professional degrees.

[†]Median and inter-quartile range are reported as data were not normally distributed. Kruskal-Wallis test results reported.

Results with a p-value < 0.05 are considered to be statistically significant. Casewise deletion was used to account for missing data in tabulating proportions and comparisons.

Total N provided separately for instances of missing data.

Participant age ranged from 21 to 80 years and 83% had a high school degree or higher level of education. Time on dialysis ranged from less than 1 year to 9 years. HD and PD patients differed in this regard, with PD participants having a median time on dialysis 3 years less than in-center HD participants (1 vs. 4 years, $p = 0.005$). Fifty-five percent reported being on the transplant waiting list. The number of patients on the transplant waiting list was greater in the PD group than

the in-center HD group (66.7 vs. 52.4%, $p = 0.8$), although this was not statistically significant. Most notably, more than 80% of participants in the PD group previously employed in-center HD while less than 30% of participants in the in-center HD group previously received in-home therapies ($p = 0.002$). Main themes extracted from focus group responses are summarized in Figure 1.

Figure 1.

Summation of Focus Group Themes

I. Experiences at Diagnosis

- Focus group participants were mixed in ESRD presentation: some were diagnosed acutely in the hospital/emergency room while others had a more chronic progression.
- Elements of fear were most commonly expressed when focus group participants spoke about how they felt about their disease when they were first diagnosed.
- Some focus group participants felt that they had been lied to or misled about the potential emotional and physical toll that dialysis could take and that they weren't given adequate information about side effects/emotional effects.
- Some participants stated they were given adequate information but were unable to process it at the time.

II. Barriers to Alternate Modalities

Barriers to peritoneal dialysis in in-center dialysis groups:

- Fear of infection
- Peer experiences with peritonitis
- Fear of isolation, no supervision
- Enjoy group atmosphere of dialysis clinic

Reasons against choosing hemodialysis in peritoneal dialysis groups:

- Fear of blood and needles
- Previous bad experience with hemodialysis

Barriers to home hemodialysis in both groups:

- Participants did not find it home hemodialysis appealing due to needing a helper, changes to their home water system, needing a room big enough for the machine and supplies and fear of having hemodialysis-related complications at home.

Barriers to transplant in both groups:

- Patients demonstrated frustration with many aspects of the transplant process including medication costs, transportation to hospital, length of time on the waiting list and the evaluation process.

Survey Demographics

Three hundred forty surveys were distributed through 4 dialysis centers and 85 surveys were distributed via the UNC kidney transplantation clinic. A total of 113 surveys were returned; 1 survey was excluded due to an excess of missing information including present modality of therapy. The remaining surveys were missing data in less than 10%

of response variables except for duration of ESRD, which was missing in 18 (15.9%) respondents (7 HD, 2 PD and 9 transplant). Of the remaining 112 survey respondents, 54 had functioning renal transplants, 20 were on PD and 38 were using in-center HD. No participants were currently using home HD (Table 2).

Table 2

Survey Participant Characteristics

	In-Center Hemodialysis (N = 38)	Peritoneal Dialysis (N = 20)	Renal Transplant (N = 54)	p-Value	Total (N = 112)
Age, yrs (SD) (N = 110)	57.8	47.1 (16.2)	49.3 (14.3)	0.01	51.7 (15.7)
Sex (%) (N = 110)	20 (52.6)	9 (45.0)	18 (33.3)	0.2	42.0
Male	18 (47.3)	11 (55.0)	36 (66.7)		58.0
Female					
Race (%) (N = 111)				0.7	
White	16 (43.2)	8 (40.0)	29 (53.7)		53 (47.8)
African American	19 (51.4)	11 (55.0)	21 (38.9)		51 (46.0)
Hispanic	2 (5.4)	0	2 (3.7)		4 (3.6)
Pacific Islander	0	1 (5.0)	1 (1.9)		2 (1.8)
Other	0	0	1 (1.9)		1 (0.9)
Education* (%) (N = 111)				0.8	
Did not graduate high school	5 (13.2)	1 (5.0)	6 (11.3)		12 (10.8)
High school graduate	11 (29.0)	8 (40.0)	21 (39.6)		40 (36.0)
> High school education	22 (57.9)	11 (55.0)	26 (49.1)		59 (53.2)
Insurance (%) (N = 111)				0.09	
None	1 (2.7)		0		1 (0.9)
Medicare	7 (18.9)	05 (25.0)	12 (22.2)		24 (21.6)
Medicare & private ins.	14 (37.8)	9 (45.0)	19 (35.2)		42 (37.8)
Medicare & Medicaid	12 (32.4)	4 (20.0)	8 (14.8)		24 (21.6)
Private ins. only	2 (5.4)	2 (10.0)	15 (27.8)		19 (17.1)
Other	1 (2.7)	0	0		1 (0.9)
Social Security assistance (%) (N = 109)	24 (68.6)	10 (50.0)	29 (53.7)	0.3	63 (57.8)
Transportation (%)				<0.001	
Drive self	15 (39.5)	16 (80)	34 (63.0)		65 (58.0)
Friend/family	11 (29.0)	4 (20)	19 (35.2)		34 (36.4)
Transport service	9 (23.7)	0	1 (1.9)		10 (8.9)
Public transport	3 (7.9)	0	0		3 (2.7)
Household income (%) (N = 105)				0.8	
≤\$10,000	7 (21.9)	2 (10.0)	8 (15.1)		17 (16.2)
\$10,001–30,000	11 (34.4)	5 (25.0)	14 (26.4)		30 (28.6)
\$30,001–50,000	4 (12.5)	6 (30.0)	11 (20.8)		21 (20.0)
>\$50,000	4 (12.5)	4 (20.0)	11 (20.8)		19 (18.1)
Do not know	3 (9.4)	2 (10.0)	2 (3.8)		7 (6.7)
Do not wish to answer	3 (9.4)	1 (5.0)	7 (13.2)		11 (10.5)
Number in household (SD) (N = 109)	1.42 (1.08)	2.60 (1.98)	1.60 (1.17)	0.005	1.72 (1.38)
Working before dialysis (%) (N = 103)	17 (44.7)	16 (80.0)	36 (80.0)	0.001	69 (67.0)
Currently employed (%) (N = 111)	5 (13.2)	6 (30.0)	20 (37.7)	0.03	31 (27.9)
Diabetes (%) (N = 109)	17 (47.2)	2 (10.0)	17 (32.1)	0.01	36 (33.0)
Duration of ESRD, median (IQR)[†] (N = 94)	2.2 (0.9, 5.5)	3.0 (1.2, 8.3)	6.3 (3.4, 10.7)	<0.001	4.4 (1.8, 9.2)
Location of ESRD diagnosis (%) (N = 106)				0.2	
Hospital/ER	17 (43.2)	5 (25.0)	14 (28.6)		35 (33.0)
PCP in clinic	4 (10.8)	5 (25.0)	11 (22.5)		20 (18.9)
Nephrologist in clinic	14 (37.8)	10 (50.0)	24 (49.0)		48 (45.3)
Don't remember	3 (8.1)	0	0		3 (2.8)
Prior modality (%)	9 (23.7)	12 (60.0)	46 (85.2)	<0.001	67 (59.8)

*Includes those who attended vocational/technical schools, college (whether or not completed) and those with graduate/professional degrees.

[†]Median and inter-quartile range are reported as data were not normally distributed. Kruskal-Wallis test results reported. Results with a p-value < 0.05 are considered to be statistically significant. Casewise deletion was used to account for missing data in tabulating proportions and comparison. Total N provided separately for instances of missing data.

Survey participants were predominantly female (nearly 60%) and ranged in age from 18 to 86 years. On average, the HD group was older than the other two groups, with mean age 57.8 years (compared with 47.1 and 49.3 years for PD and transplant, respectively [$p = 0.01$]). Transplant patients, as expected, had a longer median time of ESRD diagnosis than either HD or PD patients (6.3 vs. 2.1 and 3.0 years, $p < 0.001$). Only 10% of PD patients carried a diagnosis of diabetes compared with 32% of transplant patients and 47% of HD patients ($p = 0.01$). PD and transplant patients were more likely to be employed prior to dialysis (80% in both groups) and currently employed (more than 30% of PD patients and nearly 40% of transplant patients) than HD patients, of whom less than half

were employed prior to dialysis ($p = 0.001$) and less than 15% were currently employed ($p = 0.03$). Again, in this sampling of patients, as in the focus groups, far fewer HD patients had employed another modality for RRT.

After completing demographics information, patients filled out sections according to their modality (in-center dialysis, PD and kidney transplant). Responses were compared between HD and PD patients (Table 3). These survey responses were missing data in less than 10% of instances except for one question regarding patient's perception of the best form of RRT; six respondents did not answer this question, all receiving HD. Responses to the survey questions particular for each of the three groups separately are summarized in Table 4.

Table 3

Comparison of HD and PD patient survey responses

	In-Center Hemodialysis (N = 38)	Peritoneal Dialysis (N = 20)	p-Value
Prior nephrologist care (%) (N = 55)	23 (65.7)	15 (75.0)	0.6
Time under care of nephrologist (%)			
0–3 months	1 (4.4)	1 (6.8)	0.2
3–6 months	0	0	
6–12 months	1 (4.4)	1 (6.8)	
1–3 years	8 (34.8)	1 (6.8)	
>3 years	13 (56.5)	12 (80.0)	
Discussion of modalities (%) (N = 54)	26 (76.3)	18 (94.7)	0.2
Don't know	3 (8.6)	0	
Discussion clear (%) (N = 45)	23 (88.5)	17 (100.0)	0.7
Don't know	2 (7.7)	0	
Classes/education (%) (N = 56)	24 (66.7)	17 (85.0)	0.2
Classes/education helpful (%) (N = 40)	20 (90.9)	17 (100.0)	1
Don't know	1 (4.6)	0	
Type of education (%) (N = 42)			
Class	5 (13.2)	14 (70.0)	<0.001
Video	15 (39.5)	15 (75.0)	0.01
Literature	20 (52.6)	16 (80.0)	0.05
Other	1 (2.6)	2 (10.0)	0.3
Dialysis began emergently (%) (N = 56)	19 (52.8)	8 (40.0)	0.4
Met with other ESRD pts (%) (N = 56)	5 (13.9)	5 (25.0)	0.5
Don't know	1 (2.8)	1 (5.0)	
Most influential in choice (%) (N = 56)			0.3
Doctor	19 (53.8)	9 (45.0)	
Nurse	1 (2.8)	1 (5.0)	
Social worker	2 (5.6)	0	
Dialysis unit employee	0	0	
Friend/family on dialysis	2 (5.6)	0	
Another patient	1 (2.8)	0	
Reading materials	5 (13.9)	2 (10.0)	
Class	0	3 (15.0)	
Other	6 (16.7)	5 (25.0)	
Best option of RRT (%) (N = 52)			
Hemodialysis (in-center)	16 (50.0)	0	
Home hemodialysis	1 (3.1)	0	
Peritoneal dialysis	2 (6.3)	15 (75.0)	
Kidney transplant	13 (40.6)	5 (25.0)	
On transplant list (%) (N = 56)	9 (25.0)	8 (40.0)	0.4
Don't know	2 (5.6)	0	
Time on waitlist, yrs (SD) (N = 12)	1.42 (1.07)	2.08 (1.69)	0.4

Results with a p -value < 0.05 are considered to be statistically significant.

Casewise deletion was used to account for missing data in tabulating proportions and comparison. Total N provided separately for instances of missing data.

Table 4*Survey Respondents' Responses to Treatment-Specific Questions*

In-Center Hemodialysis (N = 38)	N (%)	Peritoneal Dialysis (N = 20)	N (%)	Renal Transplant (N = 54)	N (%)
Aware of home therapy options (N = 33) Don't know	24 (73.7) 1 (3.0)	Able to continue usual lifestyle/working	19 (95.0)	Dialysis prior to transplantation (N = 53) Type of dialysis before transplantation* In-center HD Peritoneal dialysis Peritoneal dialysis and in-center HD Home HD	45 (84.9)
Distance from dialysis unit (N = 35) <20 miles ≥20 miles Don't know	32 (91.4) 2 (5.7) 1 (2.9)	Distance from dialysis unit <20 miles ≥20 miles Don't know	9 (45.0) 11 (55.0) 0	Type transplant received (N = 47) Living related donor Living non-related donor Deceased donor Don't know	28 (62.2) 9 (20.0) 7 (15.6) 1 (2.2)
Home dialysis disruptive to lifestyle (N = 35) Don't know	18 (51.4) 6 (17.1)	In-center dialysis limiting of lifestyle	19 (95.0)	Length of time on transplant list (N = 46) < 1 year ≥ 1 year Don't know	16 (34.0) 6 (12.8) 21 (44.7) 4 (8.5)
Home less sterile than dialysis center (N = 36) Don't know	16 (44.4) 6 (16.7)	Home more sterile than dialysis center Don't know	16 (80.0) 2 (10.0)	Mean waiting time (SD) (if not < 1 year) (N = 29)	15 (32.6) 29 (63.0) 2 (4.4)
Prior home therapy (N = 36) Don't know	8 (22.2) 1 (2.8)	Prior in-center HD	13 (65.0)	Preferred type of dialysis (N = 39) Home dialysis (peritoneal or home HD) In-center HD No preference Not been on both treatments	4 (10.3) 2 (5.1) 1 (2.6) 32 (82.1)
Reason for switch from home therapy Change in home situation Recurrent infections MD felt home therapy inadequate No longer physically able	2 (25.0) 3 (37.5) 2 (25.0) 1 (25.0)	Receive better dialysis at home (N = 18)	17 (94.4)	Staff engaged in discussion of transplantation* (N = 54) Physician at dialysis unit Nurse Social worker Primary nephrologist Employee at dialysis unit Class Friend/family with transplant/on dialysis Reading materials Other	26 (48.2) 19 (35.2) 13 (24.1) 37 (68.5) 10 (18.5) 11 (20.4) 4 (7.4) 18 (33.3) 4 (7.4)
Reasons for choosing against home therapy* (N = 38) Discomfort without supervision Did not wish abdominal catheter Fear of infection/contamination Home environment not suitable Prior problem/inadequate therapy MD felt in-center dialysis was best Other	12 (31.6) 9 (23.7) 13 (34.2) 6 (15.8) 5 (13.2) 9 (23.7) 10 (26.3)	Reasons for choosing home therapy* (N = 20) Fear of needles/seeing blood Able to continue working Better for personal schedule No longer able to receive HD Knowing someone w/HD complications MD felt home therapy was best Other	3 (15.0) 10 (50.0) 17 (85.0) 0 2 (10.0) 10 (50.0) 5 (25.0)	Time first learned about transplant Before starting dialysis After starting dialysis Don't know	23 (53.5) 15 (34.9) 5 (11.6)

*Multiple responses allowed in these categories.

Casewise deletion was used to account for missing data in tabulating proportions. Total N provided separately for instances of missing data.

Experiences at the Time of Diagnosis

Patients in both PD and HD focus groups were mixed in their entry into dialysis; several had knowledge of their disease prior to reaching end stage and others had to start dialysis acutely, even emergently. In-center HD patients reported beginning dialysis acutely more often than PD patients. One respondent stated: "I went to the hospital because I had been sick and at the hospital they told me I had a heart attack which I didn't know I'd had one ... I guess they did a couple of studies on my heart and my kidneys quit working." Another participant explained: "I just got sick at work one day ... I didn't know anything. I didn't even know what dialysis was." Others, with a longer progression, felt more prepared: "I eventually had to go on dialysis...I was sort of prepared, you know ... it was not a big shock when I had to go on dialysis." Another said: "I kept going back to the same doctor and one day he said we've got to put you on dialysis, so that's how I got on."

Data from the distributed surveys (Table 2) indicated that the diagnosis of kidney disease in the acute hospital setting was relatively common overall (33%) and slightly more common among HD patients (42%). However, a substantial portion of total survey respondents (45.3%) reported that their nephrologist made a diagnosis of ESRD in a non-acute setting. Those using PD were slightly more likely to have been under the care of a nephrologist prior to initiating dialysis (75.0 vs. 65.7%), and a greater proportion of PD patients were followed by their nephrologists for more than 1 year (80.0 vs. 56.5%).

Elements of fear were most commonly expressed when focus group participants spoke about how they felt about their disease when they were first diagnosed. Participant responses included:

- "I was afraid but I wanted to live. That's what it comes down to."
- "It scared me to death when I read on a piece of paper one day. I was here and they had on there, end-stage renal disease."
- "I was just scared about whether I was going to die or not."

Choosing a Modality

Focus group participants were mixed in their perceptions of the ability to choose their treatment modalities. Some felt that they had no choice, and one patient reported that her family member made the decision for her. Others reported that the choice was made by a physician or due to complications of their prior modality (change from PD to HD due to poor Kt/V adequacy, change from HD to PD due to vascular access complications).

In speaking of her experiences with PD, one participant explained:

They came back to me and said I don't know why anybody told you that you couldn't do PD. There is no reason why you couldn't do it. And so then I went and had the PD surgery. But it was ... sort of out of my control. That was a decision that they made. I didn't really have an option.

One participant expressed her frustration with the question of choice: "You all ask like we took this by choice. We didn't have any control over this."

Regarding education received, some focus group participants felt that they had been lied to or misled about the potential emotional and physical toll that dialysis could take and that they were not given adequate information about side effects/emotional effects. A few participants had been diagnosed at a younger age and had a slow progression to kidney failure. They described feelings of denial and invincibility when they thought about the prospect of kidney failure. Other patients felt they had been given sufficient information but were not ready to process it: "I had a lot of information. I just didn't want to face the fact that I was going to go on dialysis."

Some participants were given reading materials and videos explaining modality options; some participants found this helpful, but some had difficulty understanding the materials. Participant responses included:

- "When my doctor sent me down there, they just put me in a room, showed me a film about people on dialysis, even my doctor didn't sit down and talk to me and tell me what was going on."
- "I read and read, and then I say well, maybe this means this, maybe that means that."

Participants were also sensitive to the attitudes of their dialysis caregivers, and issues of distrust and misinformation influenced how they felt about dialysis staff and the staff's ability to share with them the options for therapy. Participants in several groups felt that they had been deceived by physicians who told them they would feel better, when in reality they had not felt better at all. One participant said:

I think that one of the things we all have felt that I don't think anyone has said, is the problem of people meaning to tell us or give us a misconception of how you are going to feel. I had very high expectations and I don't do that any more. I've just started to sign up for transplant, but I don't have high expectations about that either ... I'm not going to set myself up for that again.

Another participant explained:

They said that, you know, you been having problems with your blood pressure for years and you're going to have to go on dialysis. And they said it's going to make you feel much better, you're going to do much better. That was the biggest lie they ever told.

This level of distrust led some patients to question the financial motivations of the dialysis health care staff. Participants in one PD group felt that PD was not mentioned as an option because it was not as profitable as in-center dialysis.

A majority of survey participants in both the HD and PD groups reported having discussions about modality choice, although this approached nearly 95% of PD patients compared to roughly 75% of HD patients. Most patients in both groups reported these discussions to be clear. Unlike focus group respondents, a majority of survey respondents reported some form of pre-dialysis education or class, which they reported to be overall helpful. Survey data showed more PD respondents reporting having a formal class (70 vs. 13.2%, $p < 0.001$) and having the opportunity to view a video (75 vs. 39.5%, $p = 0.01$). More than 75% of PD patients also reported having received literature regarding dialysis compared to only half of HD patients. Roughly 50% of participants on HD and PD named their physicians as being the most influential in their choice of therapy.

Perceived Barriers and Facilitators to Alternative Forms of RRT

Focus group participants cited fear as a motivating factor in many of their decisions, particularly in the choice to pursue dialysis and the choice of modality. Both groups reported a fear of blood and needles. For many in the PD group, these fears prompted an avoidance of HD: “When they sat down and they told me well one is your blood, and when I heard the word blood, you know, I was like, I’ll take the other one, I didn’t even give them a chance to tell me what the other one was.” Another person said: “Seeing your blood coming in and out...it’s something that can really scare you.”

For HD groups, fear of infection, illness and isolation at home were all motivating factors for the choice of in-center dialysis, and in many situations it was the participant’s own experience as a former PD patient or from hearing about bad cases of peritonitis from other dialysis patients. Three out of four HD groups had members who had previously been on PD and had bad experiences with that modality. Participants were hospitalized and often felt near death. These participants also felt that PD was more detrimental to the body and would erase any residual kidney function. Statements included:

- “I didn’t want to do it at home because I knew someone that had done it at home and I knew that they did catch a lot of infections and all. Most people I do know, they did catch a lot of infections at home doing it. So I said no, I don’t want the risk.”
- “Eventually the infections just took over her body. And I guess that’s what frightened me most of all was the infections.”
- “I have heard of too many people who have been on it [PD] and almost died. I will not do it.”

- “I would rather have an infection in here than peritonitis. That stuff like to have killed me. It felt like I was dying.”

Members of both HD and PD groups mentioned time constraints as a reason why PD was less desirable:

- “With the time like Tuesdays and Thursdays that I don’t have to come here, that’s great. But see, if I was doing it at home, I have to do it those days too. So that’s what bothered me about it.”
- “That’s all you do is dialyze all day long.”

Participants who had heard about home HD in both the PD and HD groups did not find it appealing due to needing a helper, changes to their home water system, needing a room big enough for the machine and supplies and fear of “bot-toming out” (dialysis-related complications) at home.

Regarding transplant, a little more than half of the focus group participants reported being on the waiting list; some patients were not sure whether they were listed and some were unable to be listed due to other medical conditions. Patients demonstrated frustration with many aspects of the transplant process including costs of medication, transportation to hospital, length of time on the waiting list and the evaluation process. Participant responses included:

- “That’s what it is, waiting. I may never get there, but I’m waiting.”
- “I’ve just started to sign up and get ready for transplant, but I don’t have any high expectations about that.”
- “Do they realize how many people can’t get there? Because if they called me today, I know good and well I can’t get there. So it’s just a waste of my time.”

Some patients reported having had family and friends engage in the organ donation process, although several reported potential donors being turned down. All felt that awareness in the general public of the need for organ donation was poor.

Among survey respondents, HD patients (Table 3) most commonly reported discomfort with no supervision, fear of infection and contamination and abdominal catheters as reasons for choosing HD over PD. Approximately 25% of patients reported that their physicians told them that HD was the best choice of therapy for them. Other reasons reported for choice against home dialysis included complications from prior PD, including peritonitis with subsequent peritoneal scarring and catheter complications, small children in the home, lack of dependability on home health providers and simply not being presented the option.

Among PD survey respondents (Table 4), the most common reasons for choosing PD were the ability to continue working and more suitability to their individual schedules. Some other reasons for choice of PD included less strict dietary restrictions, fewer infections while on PD and poor veins for HD access. One participant had been an HD nurse in the past and chose PD based on her experiences.

In contrast to the HD patients, half of PD patients reported that their physicians felt PD was a better modality for them. Of note, nearly all PD patients reported that they felt HD would be disruptive to their lifestyles. In contrast, only half of HD patients thought home therapy would be disruptive. Patients in the PD groups also tended to live farther away from their coordinating dialysis units, with nearly 55% traveling more than 20 miles. Less than 6% of in-center HD patients reported living more than 20 miles away ($p = 0.002$).

Advice to New Patients/Health Care Professionals

Although not a direct objective of the study, focus group participants were eager to discuss and suggest ways to improve education for patients approaching ESRD. Several participants described how helpful peer mentors had been in helping them cope with their own disease, or how they had mentored a patient in distress: “[The mentoree] called me a lot and she was very scared about it and all, so we talked a lot about it. And she’s fine now. I think it helps knowing somebody that’s on dialysis that you can talk to about it.” One participant speaking to another, stated: “You were the one talked me into going on PD. She said, ‘There’s someone I want you to talk to.’ You happened to be in the center one day when I was on the other side.”

A recurring suggestion from participants was for patients to be involved in their own care and not be too dependent on the health care team. For some, this seemed driven by a lack of trust in the health care team, but for others it was motivated by a feeling that self-education would increase a patient’s quality of life. Several participants felt that educating patients with kidney disease was not enough. They identified many public misconceptions of dialysis and particularly called for more education regarding transplantation. One participant stated: “‘Oh my goodness, you are getting ready to die.’ That’s the biggest misconception right there.” Another said: “The general public knows nothing about [dialysis]. I think it ought to be on TV and explained somehow that there are different kinds of dialysis. And we need kidneys donated.”

Many participants asked for more education on the mechanics of how a dialysis machine works and how to read the numbers on the machine: “I could look on my machine and see sodium on there but I didn’t know what I was looking at because nobody had never told me.”

Patients also mentioned that they wished they could have attended pre-dialysis educational sessions. One participant had taken the transplant class and another was signed up, but none of the participants mentioned a class about dialysis options. Participants in several groups felt that classes would have been a good idea, even in the hospital setting, and wished they had had the opportunity: “You’re going to be overwhelmed. But you would have a chance to ask somebody that you could actually ask questions to.” Another said: “You know they got a certain number of people got to go on dialysis at the hospital. Why not take me into a

conference room and sit down, show me some pictures, have someone come and explain what’s going on?”

DISCUSSION AND RECOMMENDATIONS FOR FUTURE RESEARCH

In our analysis, we were able to identify several factors that seemed to influence patients’ decisions in choice of RRT modality. Focus group results from this study demonstrated that, regardless of modality, fear was a guiding factor both at the time of RRT initiation and when choosing a modality. Distrust of the medical system, denial and patient experiences with previous modalities were also seen as barriers to care. Participants also reported the particular merits of their chosen modality, including impact upon schedule and perceptions of sterility and quality of dialysis.

Regarding fear as a driving factor, beyond the overwhelming fear reported at time of ESRD diagnosis, focus group participants across all groups consistently mentioned fear of side effects and undesirable characteristics of opposing modalities, including visibility of blood with HD and lack of supervision with home therapies. Survey respondents reflected these same worries in their answers for why they chose one modality over the other.

The relationship between the patient and the dialysis health care team was brought up frequently in the HD focus groups. Patients had varying degrees of trust in their health care providers (physicians, nurses, dialysis technicians and social workers). Several reported feeling like they were experimental subjects and patients often questioned the motivations of both physicians and the other dialysis staff, expressing concern that the staff simply thought of their jobs as a source of money and had no concern for the patients. Respondents also felt like physicians made decisions regarding dialysis based on what would produce the most revenue. While the relationship between patients and their dialysis providers may not have a direct correlation with modality choice, it seems important to explore in future research.

Choice was also heavily influenced by the perceived impact on lifestyle and schedule. Those who chose in-center HD preferred the well-defined schedule of thrice-weekly dialysis and saw it as far more preferable than performing dialysis on a daily basis. Home dialysis participants in both the survey and focus group cohorts preferred the autonomy offered by home therapy, and this autonomy was overwhelmingly the most commonly reported reason for choosing home therapy in the survey participants.

With regard to education, an encouraging finding among survey and focus group participants was the majority had received some form of pre-dialysis education, including classes, literature and instructional videos. Both groups in survey data reported high rates of satisfaction with their education, unlike the study performed by Rubin et al. (2004), which demonstrated a greater satisfaction in domain of information provided among PD patients. However, a major

distinction between the HD and PD groups in our study was the comprehensiveness of pre-dialysis education, which may correlate with Rubin et al.'s (2004) findings. As noted among survey participants, those receiving PD reported several more forms of education, which suggests that they received more formalized and possibly more detailed education. Although not statistically significant, perhaps the longer duration of pre-dialysis care under a nephrologist for home therapy participants may have contributed to the choice of PD. Alternatively, a more formalized education structure could be explained by the choice of PD and training necessary for home therapy. Regardless, one might infer that more comprehensive education programs could help patients in selecting home therapy.

Study limitations include a lack of generalizability due to the qualitative nature of the focus groups and small sample sizes. Although we had an overall response rate of 57%, response rates for PD and HD patients were low. Focus groups may have been biased to represent extremes of patient satisfaction—patients who are most and least satisfied with their therapy may be more likely to volunteer to express their opinions. Survey participants were overrepresented by transplant patients, as many of these patients were likely to complete and return their surveys while waiting for appointments.

Because many participants in both survey and focus group portions of the study were diagnosed in the hospital in an acute situation, or were diagnosed many years earlier, recall bias is highly likely and may alter our understanding of barriers to choice at initial diagnosis and further studies should focus on research and intervention at early and acute stages of kidney failure.

Our findings, although exploratory, can help guide further studies both of determinants of patient choice as well as interventions to assist in making choices and promoting home therapies. Despite a lack of statistical significance in this study, age, race and educational status may play a role in selection of modality and deserve evaluation in future research. Patients being treated with both home and in-center therapies expressed that while they often received education, many still harbored fears of treatment modalities and distrust of health care staff in delivering those modalities. Interventions guided to address specific patient fears of home therapies (peritonitis, isolation) and improving the patient–physician relationship could be targets to overcome perceived barriers. A broader educational approach that can occur even in the acute hospital setting may be another avenue to improve a patient's ability to choose and deserves further exploration.

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APPENDIX A

Focus Group Questions and Probes

Issue A: Dealing With Disease Onset and RRT Modalities

1. What kind of information did you get about dialysis and transplant from your health care workers?

Probe

- How were the different types of therapies presented to you, or were they presented to you at all? Who told you about them?
 - Is there anything you wish they had done or said differently?
 - Do you feel that your doctors/other health care workers gave you enough information to make a decision? Why or why not?
2. Think back to the time when you first found out that you were reaching end-stage kidney disease. What emotions were you going through at the time?

Probe

- Who told you that you were reaching end-stage kidney disease? How did they tell you?
- What did you think about dialysis before you knew you had kidney disease?

Issue B: Choosing a Modality

1. What made you decide to choose in-center hemodialysis (or PD/home HD, depending on focus group)?

Probe

- What made you decide NOT to choose an alternative treatment method?
 - Did you feel like you were ready to make a choice?
 - Were there other sources you used for information in making a decision, like friends, family members or the Internet?
2. What information do you think is most important for people to have when they are trying to figure out the treatment that is right for them?

Probe

- Looking back, what information could have been really useful to you that you did not get?
- What would you tell someone who is approaching kidney failure and trying to decide what to next?

Social Work Pioneer: Patricia M. McKeivitt, ACSW, LCSW

Joseph R. Merighi, PhD, Boston University School of Social Work, Boston, MA

The Journal of Nephrology Social Work is pleased to initiate a new “Social Work Pioneer” series. This series will feature social workers who have made substantive contributions to the nephrology social work profession through their leadership in policy, practice, research or community service.



Patricia M. McKeivitt, ACSW, LCSW

Patricia McKeivitt’s passion for the social work profession and tireless commitment to helping patients and families affected by kidney disease serve as an exemplar for the nephrology community. For the past 36 years, she has been a leader and innovator in areas such as direct patient care, social service coordination, patient education, professional development, applied research and policy formation. At the core of McKeivitt’s work is a belief that social workers have a vital role to play in promoting the psychosocial well-being of renal patients.

McKeivitt joined Barnes Hospital (now Barnes-Jewish Hospital) and Chromalloy American Kidney Center (CAKC) as coordinator of renal social work services in 1973. While on staff at CAKC, she has held various positions, including director of social work (1981–2001), research associate in medicine (1981–1991) and clinical social worker (2001 to present). In each of these capacities, McKeivitt developed materials and programs to meet the complex and changing needs of dialysis patients, families and staff. Further, her various positions at CAKC have provided her with many important opportunities to engage in cutting-edge work on issues such as older adults on dialysis, support systems in dialysis care, professional practice issues, benefits of exercise in renal patients and treatment adherence.

The primacy of McKeivitt’s work has been *advocacy* in its multiple forms: advocacy for the profession, the social work role and within the health care system and community. In addition, she has spoken eloquently and with conviction regarding the importance of nephrology social workers staying focused and setting limits; working smarter by

developing written materials and creating organizational systems to enhance information dissemination and quality control; teaching rather than doing by promoting patient self-management; using existing resources and outcomes-based approaches rather than reinventing the wheel; and engaging in ongoing professional development plans that include setting annual goals for knowledge building and bolstering practice skills.

Throughout McKeivitt’s distinguished career as a nephrology social worker, she has engaged in research and public speaking to inform the social work and medical communities about issues that affect the psychosocial functioning and well-being of renal patients. In addition, she has been a prominent voice at the national level with regard to factors that influence nephrology social work practice, such as staffing ratios, documentation and appropriate roles for social workers in dialysis units. To date, she has published 22 journal articles; delivered 45 presentations in the United States, Canada and Europe; and co-produced a video titled “Exercise in Hemodialysis” with colleagues at the Washington University School of Medicine. A selected list of publications and presentations is provided at the end of this article.

McKeivitt has served as a reviewer for the *New England Journal of Medicine*, and as a board member for *Advances in Renal Replacement Therapy, Dialysis & Transplantation* and *Perspectives: Journal of the Council of Nephrology Social Workers* (now called *The Journal of Nephrology Social Work*). She was the editor-in-chief of *Perspectives* from 1979 to 1981. In addition to her editorial contributions, she has held numerous positions of leadership in both regional and national organizations. Some of these include the National Council of Nephrology Social Workers (CNSW; president, vice president, Executive Committee chair, North Central regional representative), Missouri CNSW (president, legislative chairman), National Kidney Foundation (NKF; Executive Committee member, Scientific Advisory Board member, Patient Services Committee chairman, trustee-at-large), NKF of Eastern Missouri and Metro East CNSW (member of the Board of Directors, Executive Committee member, Scientific Advisory Board member, patient services chairman, delegate trustee), Missouri Kidney Program (Advisory Council member, Task Force on Budgets and Resources member) and the End Stage Renal Disease Network Coordination Council (social work representative, Medical Review Board member). Of particular distinction is McKeivitt’s position on the National Advisory Board of the Dialysis Outcomes and

Practice Patterns Study (DOPPS), an international research project focused on improving the morbidity, mortality and quality of life of patients on hemodialysis in 12 countries (Australia, Belgium, Canada, France, Germany, Japan, Italy, New Zealand, Spain, Sweden, the United Kingdom and the United States).

Among her many contributions to the aforementioned organizations and boards, McKeivitt was instrumental in mounting CNSW chapters in the midwestern United States, initiating the CNSW research grants program that is administered through the NKF and writing CNSW staffing guidelines. In her work at the NKF, McKeivitt promoted a national patient and family newsletter (which later emerged as *Family Focus*), organized an affiliate program-sharing manual and developed a minority outreach initiative to increase participation and programming for minority communities.

It is evident that McKeivitt's contributions to the nephrology social work profession are vast and noteworthy. Over the course of her career, she has been lauded for her work by both regional and national renal organizations. Some of these honors include an NKF of Eastern Missouri and Metro East Life Member Award, a CNSW Executive Committee Award, two NKF Distinguished Service Awards and an NKF/CNSW Lifetime Achievement Award. McKeivitt also garnered recognition outside the social work profession when she was recently awarded the Distinguished Alumna Award for Outstanding Achievement by her undergraduate alma mater, Clarke College in Dubuque, IA. This award was given to McKeivitt for her outstanding contributions to her profession and to her community.

McKeivitt is indebted to wonderful family members and colleagues for their support through the years. Of particular note are her parents, Edward and Virginia (now deceased), who set high expectations and provided the encouragement to achieve them; her sister, Judy, always a source of special support; Drs. Eduardo Slatopolsky, Herschel Harter and Vic Meltzer, who from early on understood the vital role of social work in dialysis and included social workers in policy and programming decisions; two very long-term colleagues and friends, fellow social worker Debbie Lane, LCSW, and dietitian Kathy Norwood, MS, RD, who have always been the most supportive and best colleagues for which one could hope; countless CNSW Executive Committee members whose hard work and dedication have been a source of inspiration; and, finally, her partner, Mark, for his extraordinary insight, amazing counsel and unwavering encouragement through the years.

Author's note: *To appreciate McKeivitt's steadfast commitment to helping people with kidney disease and understand her thoughts about the future of nephrology social work, I present the following excerpts from an interview conducted in August 2009.*

Merighi: What inspired you to become a social worker?

McKeivitt: There are probably many reasons, though the decision was made so long ago, it's difficult to sort all of them out. Probably the most important influence was a family value of helping others. I was encouraged to do volunteer work by my parents, so summer evenings during college I volunteered to do inner-city tutoring for grammar school children, work with patients at the Illinois Psychiatric Institute and visit patients at the Great Lakes Naval Hospital. My first exposure to medical social work was a summer secretarial job for the director of social work at St. Joseph's Hospital in Chicago. This experience was, undoubtedly, a major influence. When I was a senior in college, I needed to make a decision to either pursue advanced study in sociology or accept a National Institute of Mental Health grant for a master's degree in Social Work at Washington University. After considerable thought, I decided I would rather work directly with people and communities than focus on research and statistics.

Merighi: What motivated you to become a nephrology social worker?

McKeivitt: When I first started working in medical social work, I provided services to patients, families and staff on the neurosurgery service at Barnes Hospital in St. Louis, MO. When I was recruited by the Renal Division, I was drawn by the fact that end-stage renal disease (ESRD) requires chronic care and the opportunity to work with patients and families over extended periods of time. In 1973, the Medicare regulations covering ESRD treatment had just gone into effect, offering many more patients access to care. Transplant programs were in their early days. The number of opportunities to contribute to the care of patients and to develop projects and programs both within the medical center and the community were too exciting and challenging not to accept.

Merighi: How has nephrology social work practice changed since you started in 1973?

McKeivitt: In many ways, nephrology social work practice is both different and the same as it was in 1973. The need to educate administrations regarding the importance of the social work role in addressing psychosocial needs of patients and families has been and is an ongoing process; the need for advocacy within facilities, health care systems and communities remains. Patients' basic needs for support, counseling, education and resources are similar. Through organizations such as the CNSW, the NKF and its affiliates, the American Kidney Fund (AKF) and Life Options, as well as the efforts of countless nephrology social workers, many educational materials and programs exist for patients, families and staff. Most of these specific resources for kidney patients did not exist in the early days. Within the past several years our patient populations have continued to expand both in size and complexity and the Medicare Conditions for Coverage that went into effect in October 2008 have significantly impacted nephrology social work practice.

Merighi: In your opinion, what have been some of the biggest challenges for nephrology social work over the past 35 years?

McKevitt: The one constant challenge for the profession, and hence, CNSW, has been to advocate for the inclusion of master's of social work (MSW) services in the Medicare regulations. Other constant challenges have been to initially become included in policy and programming decisions within organizations, as well as state and local programs, to benefit kidney patients, and, now, to remain in those positions going forward. In more recent years, a major challenge is working within a field in which large, for-profit facilities dominate and, in many ways, drive priorities, staffing and, ultimately, the quality and quantity of services available to patients. Social workers are much less likely to report to a social work director or be members of a social work department, and so social workers must be their own best advocates for their role and services to patients. There are many other challenges as well with the increasingly complex patient population: those with addictions or HIV/AIDS, those from very diverse cultural backgrounds who often experience significant language barriers and those without access to health care coverage. Finally, with the latest Medicare Conditions for Coverage, social workers are truly challenged to manage Kidney Disease Quality of Life (KDQOL) tracking and reporting, and to provide the services needed and outlined in our interdisciplinary care plans.

Merighi: In your opinion, what have been some of the biggest successes for nephrology social work over the past 35 years?

McKevitt: Our major successes, in many ways, have followed our challenges and none more important than MSW services continuing as a requirement in the ESRD Medicare regulations. Nephrology social workers serve on boards and committees of voluntary organizations and government programs to influence services for kidney patients. Through national CNSW, chapters were developed, practice standards and guidelines written, publications developed, annual conferences organized, a research grants program made available, a listserv for information sharing offered and so on. Through CNSW chapters, nephrology social workers receive and give support, engage in professional development activities and are able to work cooperatively on projects, information sharing, resource development, and so on. CNSW is a wonderful success story; it's a unique social work organization established and developed by clinical social workers to advocate for patients and for the profession in countless ways.

Merighi: What would you describe as your most important contribution(s) to the nephrology social work profession?

McKevitt: As I reflect on my long career in nephrology social work, I think of all of the marvelous opportunities I've had, not only in working with patients, families and staff and in developing programs, materials and resources for them, but also the many avenues that have been available to impact

policies and programs locally, statewide and nationally. In addition, CNSW has offered many challenges and opportunities to organize and strengthen our profession, while developing into a premier clinical practice organization.

When I started in clinical practice, there were few, if any, patient or staff educational materials or programs. Within our facility and in collaboration with staff, I developed such materials as "Information to Get You Started..." (a patient orientation folder); the "Patient Information Book" (on ESRD, treatment alternatives, detailed dialysis information, community resources, etc.); an orientation group for patients and family members; a Patient Representative Committee (to address patient issues and concerns); a staff orientation program; a staff support group; a transportation resource (through the Red Cross); a CAKC patient newsletter and an Emergency Patient Fund. Other professional materials I developed included position descriptions and evaluations, a quality assurance program and a problem-oriented nephrology social work documentation system. Essentially all of these materials have been shared through the CNSW Practice Guide and national CNSW presentations and workshops.

Early on, when I found that our local NKF affiliate did not have patient services or community education programs—only a research grants program for physicians—I addressed the Medical Advisory Board to advocate for expanded programming. This resulted in the establishment of a Patient Services Committee that I chaired. We developed a variety of educational seminars, social activities, a patient/family support group and our affiliate's Patient Emergency Fund (for which I wrote the guidelines). I was also instrumental in establishing our CNSW chapter and was one of the initial co-chairs. Within the affiliate, I advocated that the "dialysis team," including nurses, social workers, dietitians and patients/family members, be involved at all levels, including the Board of Directors and the Medical Advisory Board. As a CNSW regional representative in the early days, I was involved in developing chapters in my region. This involved contacting existing groups of nephrology social workers who were already meeting and bringing them into CNSW as chapters, as well as identifying leaders who would be instrumental in developing new chapters. As part of this process, I developed a manual to assist chairs in understanding and fulfilling their roles. As CNSW vice president, among other projects, I developed the policies and procedures for the CNSW Grants Program, coordinated several grant review cycles and developed CNSW bibliographies on multiple topics to promote knowledge-based practice. As president, I was involved with many projects, including standards for practice and the nephrology social work staffing approach, as well as representing CNSW on the NKF Medical Advisory Board and Executive Committee.

On a state level, I have been involved with the Missouri Kidney Program since I began in nephrology social work, shortly after the program's inception. Initially, funds were

used essentially to buy dialysis equipment. Again, other needs, especially for medication and transportation assistance, were identified and guidelines/application procedures were developed. Advocacy for these additions to the program were approved so that all eligible Missourians could apply for needed help. Through the years, I have provided consultation to the Missouri Kidney Program, participated in many committees and served on the Missouri Kidney Program Advisory Board for 7 years.

A final area I feel strongly about is community outreach through local organizations and professional efforts. One such project I was integrally involved in was a grant from the Missouri Kidney Program, "Identifying and Treating Type II Diabetics At-Risk for Renal Disease." This was a cooperative effort between two inner-city federally funded health centers and the Washington University School of Medicine, Renal Division. Through screenings, we identified people with type II diabetes who had microalbuminuria, provided education and counseling to promote better management and automatically referred patients needing nephrology consultation to our renal clinic. Another outreach program I was closely involved with focused on providing information and encouragement for organ donation to the African-American community. As a member of the Community Advisory Board for the outreach program at Mid-America Transplant Services, I assisted with strategizing outreach efforts and developing culturally sensitive/appropriate educational materials.

Merighi: What advice would you give to the next generation of nephrology social workers?

McKevitt: My advice for the next generation of nephrology social workers is to view the challenges you face as opportunities to make a difference. Never stop advocating for your patients and the services they need and should be receiving under the Conditions for Coverage; use your negotiating and problem-solving skills with administration to continually sharpen your focus on appropriate, mandated social work services; and don't keep reinventing the wheel—there are marvelous materials for patient and staff orientation, education, staff in-services, support groups, facility programs, nephrology social work practices, KDQOL tracking and reporting and so on that can be accessed through your CNSW membership/chapter or the listserv. In practice, never forget the importance of knowledge-based practice, initial comprehensive social work assessments and supportive relationships with patients and families. Teach rather than do: empower your patients to advocate and solve problems for themselves. Remember you can't be all things to all people all of the time, so set priorities and stay focused. Finally, challenge yourselves, collaborate with colleagues or local schools of social work on projects such as outcome-based interventions, get involved with NKF and CNSW nationally and locally and serve on boards and committees to impact policies and programming.

Merighi: What do you envision for the future of nephrology social work?

McKevitt: It is, needless to say, difficult to predict the future of nephrology social work or medical social work in general, especially in light of the unknowns of health care reform and the influence of large dialysis organizations. Given the social work mandate in the Medicare Conditions for Coverage, it is anticipated that social workers will remain integral members of ESRD treatment teams. If trends continue, we will be providing services to older, more complex and more diverse patient populations. Staffing levels, appropriateness of assigned tasks and adequate time to provide mandated services will continue to be challenging. It would seem a good time for CNSW to strategize with a range of individuals and organizations to develop a multi-pronged approach for advocating adequate staffing and appropriate responsibilities for nephrology social workers. Certainly part of any strategy would be to work statewide and nationally with the Medicare survey process, so that surveyors are capable of assessing whether staffing is adequate to provide mandated services. From my perspective, review teams should include experienced nephrology social workers who know the services that should be provided, the appropriate tasks and whether patients are receiving the counseling and assistance they need and should have available to them.

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McKevitt, P. M. (1976, July). *Ethics of transplantation: Living related and cadaveric organ donation*. Paper presented at the Webster College Conference, St. Louis, MO.

McKevitt, P. M. (1978, October). *Group work in dialysis and transplantation*. Paper presented at the Western Dialysis and Transplant Conference, Honolulu, HI.

McKevitt, P. M. (1980, June). *Defining and utilizing support systems in self-care and home dialysis*. Paper presented at the Michigan Kidney Foundation Symposium, Detroit, MI.

McKevitt, P. M. (1984, October). *Exercise as a rehabilitative process*. Presentation and workshop at the 4th Psychonephrology Conference, New York, NY.

McKevitt, P. M. (1985, December). *ESRD patients: Promoting fitness and rehabilitation through exercise: Psychosocial and compliance issues*. Paper presented at the Annual Scientific Program, National Kidney Foundation, New Orleans, LA.

McKevitt, P. M. (1986, June). *Nephrology social work practice and research in the USA*. Paper presented at the European Dialysis and Transplant Nurses' Association Conference, Brussels, Belgium.

McKevitt, P. M. (1997, April). *Doing what you say, saying what you do: A workshop on nephrology social work documentation*. Paper presented at the National Kidney Foundation Spring Clinical Meetings, Dallas, TX.

McKevitt, P. M. (2001, April). *What's going on in research that has clinical implications for our practice: The Dialysis Outcomes and Practice Patterns Study*. Paper presented at the National Kidney Foundation Spring Clinical Meetings, Orlando, FL.

McKevitt, P. M. (2007, April). *Things I've learned over 30 years in nephrology social work that are relevant to practice today*. Paper presented at the National Kidney Foundation Spring Clinical Meetings, Orlando, FL.

McKevitt, P. M. (2008, April). *Celebrating CNSW, celebrating us: An overview of the Council's accomplishments and nephrology social work challenges*. Paper presented at the National Kidney Foundation Spring Clinical Meetings, Dallas, TX.

McKevitt, P. M., & Whitlock, M. (1986, May). *Community based screening and intervention program for type II diabetics at-risk for renal impairment*. Paper presented at the Region VII Conference on High Blood Pressure, Kansas City, MO. [JNSW](#)

Emotional Exhaustion and Workload Demands of Kidney Transplant Social Workers

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This exploratory study examined training issues, emotional exhaustion and workload demands in U.S. kidney transplant social workers. Online survey data were obtained from 91 respondents who represented all 18 End-Stage Renal Disease networks. Findings indicated that the majority of the respondents' employers provided resources for educational training and paid time off associated with these trainings. With regard to hours per week spent on specific job tasks, respondents indicated that pre-transplant activities were the most time-consuming, followed by post-transplant and inpatient work. Generally, emotional exhaustion and workload demands were slightly lower than reported for dialysis social workers. Implications for social work practice and research are discussed.

INTRODUCTION

People with chronic kidney disease (CKD) require a range of psychosocial services and interventions from social work practitioners. These services and interventions help patients manage the physiological and psychological sequelae associated with the disease process. Studies have demonstrated that social work interventions such as counseling and education have a positive effect on patients' psychological well-being and psychosocial adjustment (Beder, 1999; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2001). The nature of CKD and the invasiveness of a treatment such as transplantation create multiple psychosocial stressors for renal patients, such as cognitive losses, social isolation, bereavement, depression, anxiety, psycho-organic disorders, somatic symptoms, economic pressures, insurance and prescription issues, employment and rehabilitation barriers, mood changes, body image issues, concerns about pain and diminished quality of life (DeOreo, 1997; Katon & Schulberg, 1997; Kimmel et al., 2000; Levenson & Olbrisch, 2000; Mapes et al., 2004; Rabin, 1983; Rosen, 1999; Vourlekis & Rivera-Mizzoni, 1997). Psychosocial factors, such as limited finances, depression, relationship changes and employment concerns, have been shown to result in transplant immunosuppressant medication non-compliance (Russell & Ashbaugh, 2004).

In the case of CKD patients who elect to have kidney transplants, hospital- and clinic-based social workers are central to the provision of transplant-specific education, psychosocial support and case management services. However, these social workers can face many workplace challenges that affect their overall job-related well-being. Some of these challenges may include limited professional autonomy (Kim & Stoner, 2008), large caseloads (Merighi & Ehlebracht, 2004a), ethical conflicts (O'Donnell et al., 2008) and a lack of support for their unique social work role (Um & Harrison, 1998). For instance, studies have reported that social workers are at risk of experiencing high levels

of stress or burnout when they experience role conflict or when their professional role is not recognized (McLean & Andrew, 2000; Um & Harrison, 1998).

EMOTIONAL EXHAUSTION AND WORKLOAD

Studies of emotional exhaustion began with Maslach's (1982) path-breaking research on burnout. In this research, Maslach devised a model of burnout that is comprised of three parts: emotional exhaustion, depersonalization and reduced personal accomplishment. The first component of the burnout model, emotional exhaustion, is characterized by a chronic state of feeling emotionally drained, being physically fatigued and having depleted emotional resources. The second component, depersonalization, is characterized by an inability to form interpersonal connections with others, such as patients, clients and coworkers. The third component, reduced personal accomplishment, is characterized by negative self-evaluations in which a person feels that she or he is incompetent and ineffective. Empirical investigations have shown that emotional exhaustion is a significant predictor of job performance (Wright & Cropanzano, 1998) and commitment to an organization (Cropanzano, Rupp, & Byrne, 2003).

In addition to feeling emotionally exhausted as a result of one's job, a person's perception of her or his workload can also contribute to negative occupational health outcomes. According to Spector and Jex (1998), "workload can be measured in terms of the number of hours worked, level of production, and even the mental demands of the work being performed" (p. 358). Spector and Jex developed a brief workload measure—the Quantitative Workload Inventory (QWI)—that can be used to assess workload in terms of pace and volume. In their meta-analysis of 18 studies used to demonstrate the validity of the QWI, Spector and Jex reported that the QWI is strongly correlated with the experience of role conflict and frustration in one's job. As the professional role and responsibilities of social workers

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begin to be more clearly defined in terms of patient caseloads, involvement in non-clinical activities and job satisfaction (see Merighi & Ehlebracht, 2004a, 2004b, 2004c), the influence of emotional exhaustion and workload on renal social workers' professional practice and occupational well-being merit further investigation (see Merighi & Ehlebracht, 2005).

Currently, little empirical research has been conducted to examine the job roles, occupational well-being and practice expertise of kidney transplant social workers. The proposed study extends Merighi and Ehlebracht's work with dialysis social workers by focusing specifically on social workers employed in kidney transplant facilities. Three research questions guided the proposed study: (1) Do transplant social workers receive concrete support from their employers to engage in job-specific training? (2) To what degree do transplant social workers experience professional autonomy and acknowledgement of their social work role? (3) To what extent do transplant social workers experience emotional exhaustion and workload demands in their day-to-day practice?

METHODS

Study Design

A cross-sectional research design was used to conduct an online survey of social workers employed in kidney transplant facilities across the United States.

Respondents

A sample of 91 respondents was used for this study. The respondents were obtained by generating a list of all U.S. kidney transplant facilities as of April 2007 ($N = 247$). A complete list of these facilities was obtained from the End-Stage Renal Disease (ESRD) Network and cross-checked with facility data maintained by the United Network for Organ Sharing (UNOS). The overall response rate was 37%. The sample consisted of 93.0% Whites, 3.5% African Americans, 2.3% Hispanics/Latinos and 1.2% Asians/Pacific Islanders. The respondents' mean age was 44.6 years ($SD = 11.2$), with an average of 16.8 ($SD = 10.2$) years of social work practice experience, 12.97 ($SD = 8.8$) years of medical social work experience, and 6.34 ($SD = 5.9$) years of transplant social work experience. The majority of the respondents were women (91%) and worked full-time ($M = 38.0$ hours per week, $SD = 10.0$). Kidney transplant social workers from all 18 ESRD Networks are represented in this study.

Measures

A 177-item Kidney Transplant Social Worker Job Survey was used to evaluate renal social work practice in three broad domains: professional development and training, job-related issues and patient care. Both open- and closed-ended questions were used in each of the aforementioned domains. The survey was reviewed by seven expert kidney transplant social workers to enhance its face validity, and pretested with three social workers to assess its ease of use. The two outcome measures for the descriptive analysis in this article include emotional exhaustion and workload, as described in the following paragraphs.

Job-Related Emotional Exhaustion (JEE). The JEE was used to measure how often respondents felt "used up" as a result of their work (Wharton, 1993). This measure consists of six items rated on a 7-point scale, from 0 ("Never felt this way while at work") to 6 ("Felt this way every day"). Sample items included, "I feel emotionally drained from my work," "I feel frustrated by my job" and "I feel I'm working too hard on my job." The JEE total score ranged from 0 to 36, with high scores being indicative of a high level of emotional exhaustion. A mean score of 14.8 ($SD = 7.7$) was obtained from a study of 622 hospital and bank employees (Wharton, 1993). Cronbach's alpha for the current study was 0.94.

Quantitative Workload Inventory (QWI). The QWI was used to measure the pace and volume of work that is associated with the respondent's job (Spector & Jex, 1998). This measure consists of five items coded on a 5-point scale, from 1 ("Less than once per month or never") to 5 ("Several times per day"). Sample items included, "How often does your job require you to work very fast?" "How often is there a great deal to be done?" and "How often do you have more work than you can do well?" The QWI total score ranged from 5 to 25, with high scores corresponding to high workload level. A weighted mean score of 16.5 ($SD = 3.4$) was obtained from 15 studies with 3,728 participants (Spector, n.d.). Cronbach's alpha for the current study was 0.91.

Data Collection Procedure

For this study, the data collection procedure consisted of sending a brief, introductory letter to all 247 kidney transplant facilities in the United States and requesting that the social worker use the enclosed Uniform Record Locator (URL) to access the survey. Because the survey was anonymous, letters were addressed to the "Kidney Transplant Social Worker." In addition, an electronic copy of this letter was distributed via the Council of Nephrology Social Workers listserv, and an announcement about the research was posted on the Society for Transplant Social Workers website. Study respondents were asked to type the URL into their Web browser to access the survey. The first page of the survey consisted of an informed consent document that provided details about the research, risks and benefits associated with participation and a description about the voluntary nature of this project. The survey took approximately 40 minutes to complete. No compensation or incentives were offered in exchange for completing the survey. This study was conducted with institutional review board approval from Boston University.

RESULTS

Overall, the majority of respondents reported that their employers provide resources for professional training, education and travel. Specifically, 60% of employers provide social work-specific in-service training, 89% provide paid education time off, 77% reimburse for educational classes or workshops and 72% pay for work- or education-related travel expenses.

Professional support and autonomy were assessed to gauge the degree to which the respondents believed members of other disciplines recognized their role and contributions to the transplant teams (Table 1). Generally, more than three-fourths of the respondents reported that they were often, very often or always considered an equal partner on the transplant team, respected by other disciplines and able to make autonomous decisions.

Table 1

Kidney Transplant Social Workers' Perceptions of Support for Their Practice

Domain	Percent (%)		
	Rarely, never or sometimes	Often	Very often or always
Are you an equal partner/member of the interdisciplinary team?	25.3	24.2	50.5
Do the physicians/surgeons recognize and respect your social work role?	24.2	22.0	53.8
Are your autonomous decisions respected by the team?	19.8	20.9	58.3
Does your direct supervisor recognize and respect your social work role?	17.6	13.2	69.2
Do you make autonomous decisions regarding your social work practice with patients?	3.3	17.6	79.1

Job demands were examined in three domains: hours per week spent on distinct transplant-related issues; hours spent assisting patients, family members, colleagues and others in a typical workday; and assessment of workload demands. Respondents described time spent per week on specific activities as follows: 19.1 hours on pre-transplant, 6.8 hours on inpatient, 12.7 hours on post-transplant, and 8.1 hours on patient crises. With regard to activities that involve contact with people either in person or by phone, study respondents indicated that they assist an average of 12.8 people in a typical workday.

The QWI was used to measure the pace and volume of work that is associated with the social worker's job on the transplant service. See Table 2 for a breakdown of all six QWI items by response choice. The overall workload demands score for this sample was 18.3 ($SD = 5.1$), which is higher than the aggregate score of 16.5 ($SD = 3.4$) reported by (Spector, n.d.). However, it is nearly equal to or somewhat lower than scores reported by Merighi and Ehlebracht

(2005) in their study of dialysis social workers who work 35 or more hours per week in three distinct settings: private for-profit units ($M = 18.4$, $SD = 4.4$); private nonprofit units ($M = 18.9$, $SD = 4.5$); and public units ($M = 19.9$, $SD = 5.4$).

Table 2

Workload Demands Summary

Domain	Percent (%)
Work very fast at least several times a day	26.4
Have little time to get things done at least several times a day	27.9
Have more work than can be done well at least several times a day	28.9
Work very hard at least several times a day	35.2
Have a great deal to be done at least several times a day	47.3

The JEE was used to measure how often respondents felt "used up" as a result of their work. The mean emotional exhaustion score for this sample was 15.1 ($SD = 9.7$), which is similar to the score of 14.8 ($SD = 7.7$) that was obtained from a study of 622 hospital and bank employees (Wharton, 1993). However, Merighi and Ehlebracht (2005) reported higher scores in their study of full-time dialysis social workers (35 or more hours per week) in three distinct settings: private for-profit units ($M = 15.9$, $SD = 9.0$); private nonprofit units ($M = 16.1$, $SD = 8.1$); and public units ($M = 19.4$, $SD = 8.1$).

DISCUSSION

Few studies have examined the emotional exhaustion and workload demands of social workers in health care settings. The current study provides a descriptive examination of nephrology social workers who comprise a highly specialized area of social work practice in health care. It is encouraging that a majority of employers recognize the importance for kidney transplant social workers to stay current with regard to professional education and training, and value professional development by supporting such endeavors. Further, it is promising that many kidney transplant social workers report that their professional colleagues recognize the value of having a social worker on the interdisciplinary team to assist patients with psychosocial barriers to clinical care outcomes.

It is noteworthy that kidney transplant social workers spend approximately 13 hours per week helping patients who have received a transplant. This time commitment, along with the 8 hours per week spent on patient crises, is important to highlight to kidney transplant programs as they perform job analyses related to kidney transplant team personnel and

determine whether enough social work hours are devoted to kidney transplantation. As the ultimate goal of kidney transplant programs is for patients to live long and healthy lives with the transplanted organ, kidney transplant social workers are spending almost as much time on crises and post-surgical issues as they are on pre-transplant workups. This reality may require a paradigm shift in some kidney transplant programs that may assume the majority of kidney transplant social work tasks involve pre-transplant workups.

The quantitative workload inventory findings suggest that kidney transplant social workers have a faster pace and higher volume of work tasks than other professionals, which is similar to dialysis social workers. This finding suggests that, like dialysis social workers, kidney transplant social workers may be more susceptible to burnout than other professionals. The consequences of burnout in this context consist of negative health outcomes for the social workers, significant financial costs for the transplant program if a social worker quits or calls in sick and, most importantly, possible poor patient outcomes if a skilled kidney transplant social worker is unavailable to assist patients in an optimal manner.

It is encouraging, however, that kidney transplant social workers may have less job-related emotional exhaustion than dialysis social workers. This finding may be explained by the high level of employer investment in professional education and the recognition and support of the interdisciplinary transplant team, all of which help alleviate job-related emotional exhaustion. Future research is needed to explore this multivariate relationship and test whether emotional exhaustion can mediate the relationship between workload demands and occupational outcomes.

The study's limitations include its cross-sectional design, response rate, selection bias and social desirability bias. This study used a cross-sectional design, which is common in survey research studies; unfortunately, it obtained information at one point in time and did not capture social processes or change (Rubin & Babbie, 2005). Social workers may have responded to items based on how they felt the particular day they responded to the survey and the feelings they reported may not be reflective of how they generally feel. The response rate in this study was low, as is typical for mail surveys (i.e., typically 10–50%; Kreuger & Neuman, 2006; Neuman, 2000). It is important to note, however, that the study sample represents approximately one-third of the kidney transplant social worker population in the United States. A social desirability bias may also influence how respondents replied to sensitive items and may have even excluded some from participating in the survey; however, self-report is a common method to collect data. Despite these limitations, this is an important small-scale study of kidney transplant social workers' occupational well-being. As such, this study provides important pilot data for future investigations.

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**SOCIAL WORK ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION
2010 SPRING CLINICAL MEETINGS**

Chronic Kidney Disease

- 5 CKD and Older Adults: A Review and Implications for Social Work Practice and Research**
Tiffany Washington, University of North Carolina, Chapel Hill, USA

Hemodialysis: Other

- 1 Reducing Behavior-Based Missed Hemodialysis Treatments**
Stephanie Best, Bart Canny, Emily Averette, David Cameron, David Keaveney, Janel Anderson, Gemini Stroman, Jennifer Felts, David Lapinski, Helen Grammas, Hollie Russ, DaVita, Inc, Lakewood, CO, USA
- 2 Helping Adult Hemodialysis Patients Self-Manage Oral Medications: Recommendations from the Literature**
Teri Browne¹ & Joseph R. Merighi²
¹University of South Carolina, College of Social Work, Columbia, SC, USA; ²Boston University, School of Social Work, Boston, MA, USA
- 3 Improving the Dialysis Experience with the Use of Technology**
Karen Crampton
University of Michigan Dialysis Services, Ann Arbor, MI, USA
- 4 Health Disparities/Inequities in End Stage Renal Disease**
Carla Ford-Anderson
Nephro-Care West, Inc., Brooklyn, NY, USA

1. REDUCING BEHAVIOR-BASED MISSED HEMODIALYSIS TREATMENTS

Stephanie Best¹, Bart Canny¹, Emily Averette¹, David Cameron¹, David Keaveney¹, Janel Anderson¹, Gemini Stroman¹, Jennifer Felts¹, David Lapinski¹, Helen Grammas¹, Hollie Russ¹
¹DaVita, Inc, Lakewood, CO, USA

Hemodialysis (HD) patients not receiving their full prescribed treatment or complete treatment schedule have been associated with a higher mortality risk. We examined the missed treatment rate and performed a root cause analysis for missed treatments in 11 North Carolina HD centers. We then provided focused patient education and individualized social work interventions for a period of 12 months to reduce the rate of missed treatments. This education focused on the impact of patient non-adherence on their health and included interventions such as teaching patients relaxation techniques, providing direction for substance abuse treatment, or solving scheduling issues within the clinic. Centers also offered rescheduled appointments when a treatment was missed. Our assessment found that “problems adjusting to their treatment lifestyle” was the top self-reported reason for missed treatments within a patient’s control. Previously diagnosed mental health issues were also common in patients who frequently missed treatments. Of the patients who received a Social Work intervention, missed treatments were reduced or eliminated in 71% of patients. The overall missed treatment reschedule rate doubled from 0.35% of total treatments in the clinics during July 2007 to 0.68% in June 2008. In June 2008, the combined missed treatment rate for non-adherence was 1.77% compared to a baseline rate of 4.22% in July 2007. Social work intervention reduced the rate of missed treatments and improved the reschedule rate. This improved patient adherence, especially in patients deemed “unreachable,” was a key component to improving treatment outcomes and decreasing mortality thus highlighting the valuable role of social workers within the interdisciplinary dialysis team.

2. HELPING ADULT HEMODIALYSIS PATIENTS SELF-MANAGE ORAL MEDICATIONS: RECOMMENDATIONS FROM THE LITERATURE

Teri Browne¹ & Joseph R. Merighi²

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Adult hemodialysis patients take a variety of oral medications to manage their kidney disease and concurrent illnesses, with one recent study reporting that one-half of patients take 19 pills or more per day (almost half of these pills are phosphorous binders).¹ Despite the fact that self managing these medications is a critical component of good clinical outcomes, more than half of hemodialysis patients may not take their medications as prescribed. A literature review was conducted to examine adult hemodialysis patient barriers to oral medication self management. An online search was conducted from March 2009 to May 2009 using MEDLINE, PubMed, Ovid, CINAHL, and PsychLIT databases to identify research and summarize findings from meta-analyses, systematic reviews, clinical reviews, and clinical trials published in English between January 1985 and May 2009, as they relate to oral medication adherence in kidney disease and other chronically ill populations. The results of this literature search suggest that barriers to adult hemodialysis oral medication self-management are multi-faceted, and relate to the burden of taking pills, demographic and socioeconomic variables, psychosocial factors, health literacy, patient satisfaction, and health beliefs. In addition to future research in this area, hemodialysis teams can help patients ameliorate these barriers through interdisciplinary interventions related to self-management training, medication dosing, health literacy, improving communication, and increasing patient self-efficacy.

1. Chiu Y-W, Teitelbaum I, Misra M, de Leon EM, Adzize T, Mehrotra R. Pill burden, adherence, hyperphosphatemia, and quality of life in maintenance dialysis patients. *Clinical Journal Of The American Society Of Nephrology: CJASN*. 2009;4(6):1089-1096.

3. IMPROVING THE DIALYSIS EXPERIENCE WITH THE USE OF TECHNOLOGY

Crampton, Karen

University of Michigan Dialysis Services, Ann Arbor, MI

Certain distraction methods have been reported to reduce pain, lower blood pressure, decrease anxiety, and improve overall sense of well-being. In dialysis units, the addition of televisions has provided a welcomed distraction for patients that sit for 3, 4 or more hours each treatment.

In order to expand upon some of these benefits, additional distraction methods were introduced at University of Michigan Dialysis Services. In particular, we made digital music players (Apple's iPod Touch™) and Internet-connected laptop computers available for patients to use during dialysis. Our initial observations show that these technologies offer potential benefits to patients.

Digital music players such as the iPod allow patients to listen to their favorite artist/genre, guided imagery, and relaxation music. Music can be a stimulus for active focus, redirection, or distraction from dialysis. As a result it may have the capacity to reduce pain, lower blood pressure, decrease anxiety and improve overall sense of well-being, all of which may decrease shortened and missed treatments.

Laptop computers provide multiple opportunities for distraction, allowing patients to watch movies, play games, check email, or do personal business. As an additional benefit, laptops in the clinic can help to enhance the technological skills of patients, allowing them to learn to use the Internet, and access renal consumer education and support websites. This can increase self-efficacy and enhance skills that have value outside the clinic.

Our project has revealed both benefits and challenges. Patients have reported several positive impacts, including increased motivation to complete their treatment, improved night time sleep, and improvements in mood. Some patients have shown reluctance to adopt the new technology, possibly due to embarrassment around their limited computer skills. While several staff members are enthusiastic, others have expressed concern about the increased burden on their time and responsibilities. Thus far, the positives have outweighed the negatives and have proved significant enough to sustain this beneficial program.

5. CKD AND OLDER ADULTS: A REVIEW AND IMPLICATIONS FOR SOCIAL WORK PRACTICE AND RESEARCH

Tiffany Washington, University of North Carolina, Chapel Hill, USA

Purpose: The elderly are the fastest growing segment of the ESKD population. By the year 2030, older adults will constitute well over half of persons living with CKD. In light of the increased prevalence of older persons in all stages of CKD, social work interventions must apply to older adults. The purpose of this review is to address two important questions: (1) to what extent do social work journals contain research about older adults with CKD?; and (2) does the research offer implications for social work practice and research?

Methods: Articles published between the years 1998 and 2008 were reviewed. Scholarly articles were selected from health-related social work journals: *Health & Social Work*, *Journal of Nephrology Social Work*, *Social Work in Health Care*; and *The Journal of Gerontological Social Work*. Table of contents and abstracts were reviewed for aging and kidney content using the search terms, "renal", "nephrology", "kidney", "aging", "elderly", "older", "gerontology", and "geriatrics". An article met the criteria if the content was research based and addressed implications for social work practice with older adults in dialysis and transplant patients or implications for research on older adults with CKD.

Results: Close to 1,000 articles were reviewed. Of those, 4 articles met the review criteria. These articles addressed practice implications such as the need for psychosocial evaluation, assessment, and education. Implications for research were provided in 1 abstract.

Conclusion: There is a remarkable gap in research with older adults with kidney disease. The majority of health and aging social work research focuses on persons with cancer, diabetes, and HIV/AIDS. Geriatric kidney patients experience visual and hearing impairment, malnutrition, cognitive impairments, urinary incontinence, and limited functional status and psychosocial issues including lack of social support, economic hardships, and isolation. Social work interventions on self-care, functioning, and quality of life are critical to the well-being of a burgeoning high risk and vulnerable population.

4. HEALTH DISPARITIES/INEQUITIES IN END STAGE RENAL DISEASE

Ford-Anderson, Carla, Nephro-Care West, Inc., Brooklyn, NY

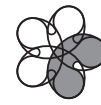
The purpose of this study is to examine the differences in the rate of increase of End Stage Renal Disease between Whites, African-Americans and Hispanics and the rate of increase in diabetes and hypertension, two of the main causes of ESRD. In the United States, as of December 31, 2007, there were 527,283 people with ESRD. In 2007, 111,000 people started dialysis. There were 57,213 people with ESRD in 1980 (USRDS, 2009).

Methods: Examination of the data compiled by the USRDS in their Annual Data Report for 2007 provides information about the incidence and prevalence of ESRD by race and ethnicity and by primary cause. This information allows one to observe the differences and draw inferences from the data.

Results: The median age for ESRD patients in 2007 was 59.1 years, varying among ethnic groups from a high of 60.3 years for Whites to a low of 57.1 years for African-Americans. The point prevalence rate among African-Americans was 5,111 per million population compared to 1,911 for Asians and 1,231 for non-Hispanic Whites. The point prevalence rate for Hispanics was 2,408 per million population, almost 50% higher than that of non-Hispanic Whites (1,613). In 1980 glomerulonephritis was the leading (42%) cause of ESRD, with diabetes a distant second at 17%. In 2007, diabetes was the primary cause of ESRD. African-Americans begin dialysis at an earlier age and also have the highest rate of diabetes and hypertension, followed by Hispanics. Both groups have a higher rate of diabetes and hypertension than Whites (USRDS, 2009).

Conclusions: Based on the information in the USRDS, one can infer that the rate of ESRD, diabetes and hypertension is greater in minorities than in Whites. One can then conclude that health disparities and inequities exist between Whites and minorities living with ESRD.

CNSW Research Grants Program



National Kidney
Foundation®

Council of Nephrology
Social Workers

PURPOSE

In keeping with the overall goals of the National Kidney Foundation (NKF) and its Council of Nephrology Social Workers (CNSW), the purpose of the CNSW Research Grant Program is to further knowledge of psychosocial factors in kidney failure and to enhance clinical social work intervention with dialysis and transplant patients/families.

AREAS OF INTEREST

- Research on psychosocial factors in kidney failure
- Clinical practice research projects focusing on social work assessment and treatment strategies with patient/families or staff
- Educational programs to enhance patient/family understanding of kidney failure treatment and its psychosocial implications
- Pilot or demonstration projects which have broad applicability to nephrology social work services and/or nephrology social workers

ELIGIBILITY

Grant applications must meet the following eligibility requirements:

- Regular membership in CNSW
- Minimum of two years nephrology social work experience (CMS Guidelines)
- Approval of the department head or facility director of the organization within which the research is to be conducted
- Residence in the United States or its territories
- Applicant must meet the definition of a “qualified social worker” as stated in the Conditions for Coverage

Preference will be given to applicants who:

- Have ACSW accreditation or are licensed by their state

Awards will be announced in March. The Review Committee reserves the right to award grants or to decline funding without stating its reasons.

GRANT REQUIREMENTS

Each grant recipient is responsible for:

- Conducting the project as set forth in the proposal and consistent with accepted, systematic research methods

- Obtaining appropriate human studies clearance within the dialysis/transplant facility and maintaining data in a confidential manner
- Completing the project within the specified time frame
- Providing financial reports as required by the National Kidney Foundation
- Acknowledging NKF/CNSW grant assistance on all publications arising out of the work done during the duration of the grant
- Submitting three interim progress reports and other requested reports, preparing a final report of the work accomplished within 60 days of the end of the grant year, and presenting a paper at the NKF Spring Clinical Meetings describing the research, results and implications for practice
- Submitting a manuscript based on the results to *The Journal of Nephrology Social Work* (and with the committee’s approval, another related journal)

FUNDING

- CNSW annually requests grant monies from NKF.
- One or more grants will be awarded. Applicants submitting to more than one granting agency will be awarded the difference between the amount awarded by the other agency and the amount applied for from CNSW.
- CNSW grants assist in defraying the cost of research and projects. They are not intended to cover the entire cost of the research (i.e., office space, basic supplies, services, overhead, administration fees).
- Funds may not be used for the purchase of equipment.
- Budgets must allocate \$750.00 for airfare and one night’s accommodation to enable grantees to present their research at the NKF Spring Clinical Meetings. This amount will be withheld until the first draft of the manuscript is received by the *Journal of Nephrology Social Work* co-editors and the awardee has presented findings at the next NKF Spring Clinical Meetings.
- Funding for CNSW research grants runs from July 1 of the year of approval through June 30 of the following year.

CNSW Research Grants Program *(cont'd)*

HOW TO APPLY

If you are interested in preparing a proposal, please submit a letter of intent to the CNSW Research Grant Program, c/o the National Kidney Foundation by **October 15**. Your letter of intent is not part of your actual application, but rather a device to assist you and the grants coordinator in identifying your research objectives and goal. The letter of intent must include the following:

1. Name of the person and organization submitting the proposal
2. Address
3. Telephone number
4. Name of the principal investigator and his or her CNSW membership number
5. Short title of the project
6. Approximate cost
7. Brief abstract under 250 words, which includes:
 - a. A description of the project goal
 - b. How it relates to the purpose of CNSW research

Upon receipt and acceptance of your letter of intent, NKF-CNSW will send you a grant application packet.

CONSULTATION COMMITTEE

CNSW has volunteer consultants available to provide recommendations and prior review of your proposal. For more information, please contact your CNSW Region Representative or the CNSW Chair-Elect.

Review Schedule

October 15	Letter of intent due
December 1	Grant Proposal due
January – February	Council Research Grants Committee Review
March	Awards Announced
July 1	Approved projects begin operation and continue until June 30th of the following year.

The Council of Nephrology Social Workers (CNSW) is a professional organization established by nephrology social workers in 1973. CNSW is one of four Professional Councils of the National Kidney Foundation (NKF). The functional structure of CNSW includes an Executive Committee with regional representation, standing and ad hoc committees, and local chapters.

For more information contact:

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www.kidney.org/professionals/CNSW

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