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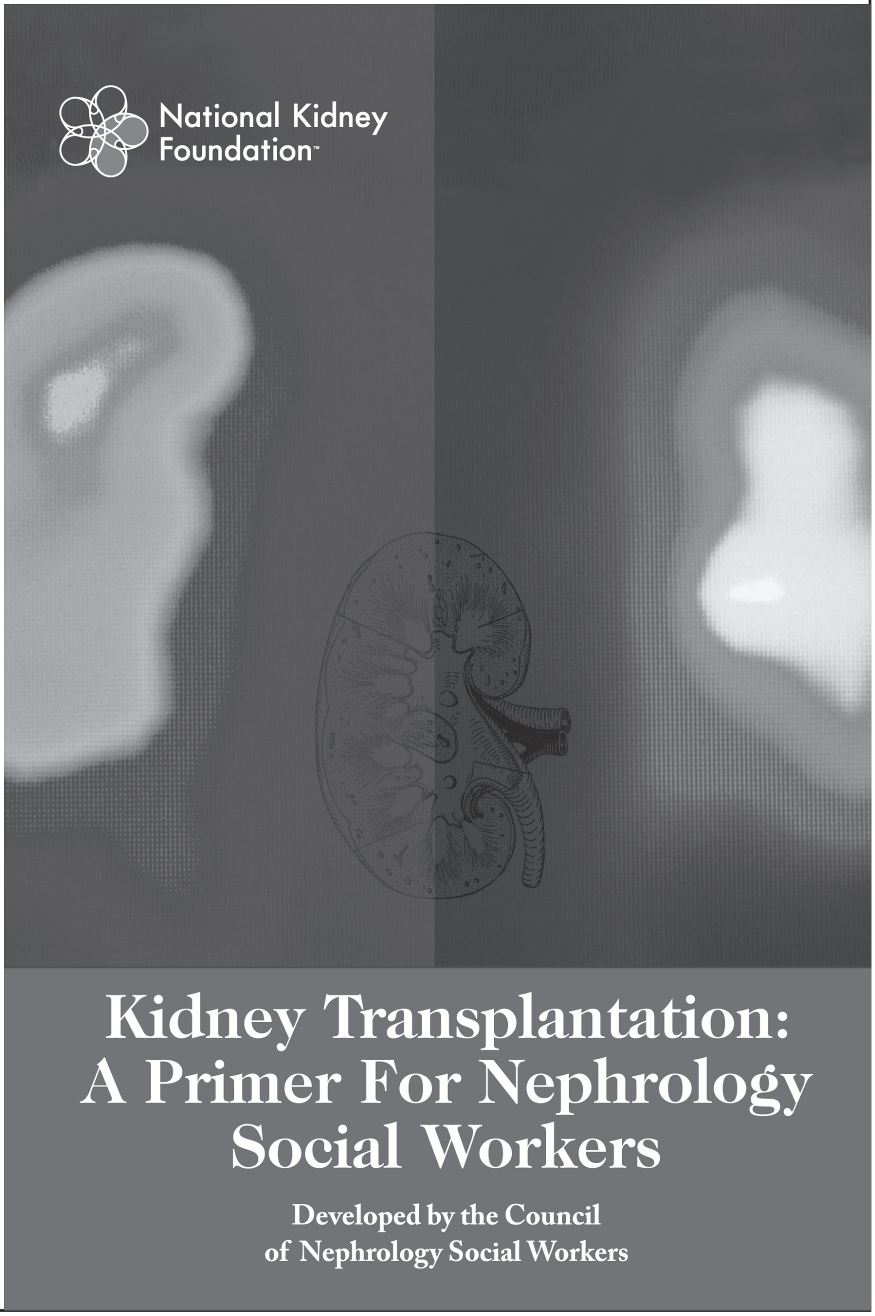

National Kidney Foundation™

Kidney Transplantation: A Primer For Nephrology Social Workers

Developed by the Council of Nephrology Social Workers

THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of nearly 900 social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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ISSN 1532-0863

The Journal of Nephrology Social Work is published by the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Professional membership in the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. ($70.00 annually domestic and $85.00 international) includes subscriptions to *The Journal of Nephrology Social Work, Renalink* and selected materials as they are published by the National Kidney Foundation, Inc. Further membership information is available from the National Kidney Foundation at 800.622.9010 or from the CNSW Web site at **www.kidney.org** or by contacting the CNSW Publications Chair Megan Prescott, LCSW, FMCNA, at **mjp313@comcast.net**

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CALL FOR MANUSCRIPTS

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

- Social Work Outcomes
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- Pediatric Issues
- End-of-Life Concerns
- Sleep Disorders
- Sexual Functioning
- Aging and Gerontological Issues
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- Quality of Life
- Ethics

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INSTRUCTIONS FOR AUTHORS

The Journal of Nephrology Social Work (JNSW) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate interest and research in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original communications and research that maintain high standards for the profession and that contribute significantly to the overall advancement of the field.

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A submitted manuscript should be accompanied by a letter that contains the following language and is signed by each author: "In compliance with Copyright Revision Act of 1976, effective January 1, 1978, the undersigned author(s) transfers all copyright ownership of the manuscript entitled ______ to *The Journal of Nephrology Social Work* **in the event this material is published."**

To qualify as an original manuscript, the article or a version of the article must not have been published elsewhere. Author(s) must inform the editor if the manuscript is being reviewed for publication by any other journals. Once accepted for publication by the editor, the author(s) cannot make revisions on the manuscript.

TYPES OF ARTICLES BEING SOUGHT

Research and Review. The *JNSW* welcomes reports of original research on any topic related to renal social work. The editors will also consider articles that document the development of new concepts or that review and update topics in the social sciences that are relevant to professionals working in the field of renal social work.

Reports and Commentary. The *JNSW* welcomes articles that describe innovative and evaluated renal social work education programs, that report on viewpoints pertaining to current issues and controversies in the field, or that provide historical perspectives on renal social work.

Reviews. Review articles—in traditional or meta-analysis style—are usually invited contributions, however, letters of interest are welcome.

Original Research. Full manuscript format should include: introduction, methods, results, and discussion of original research. Length usually should not exceed 15 double-spaced pages, including references.

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

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

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

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

MANUSCRIPT SUBMISSION

Manuscript Format

Manuscripts should be formatted according to the rules laid out by the *Publication Manual of the American Psychological Association, Fifth Edition*. What follows is a brief synopsis of the broader style points used by the APA.

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Order of the Manuscript Sections

- Title page
- Abstract
- Text
- References
- Appendixes
- Author note
- Footnotes
- Tables
- Figure captions
- Figures

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Abstract. The manuscript's abstract should be set on its own page, with the word “Abstract” centered at the top of the page. The abstract itself should be a single paragraph with no indentation and should not exceed

120 words. All numbers—except for those that begin a sentence—should be typed as numerals. Running heads and page numbers should continue from the title page.

Text. The text (or body) of the manuscript should begin on a new page, after the abstract. The title of the manuscript should be set at the top of the first page, centered and double-spaced. Running heads and page numbers should continue from the abstract.

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Table footnotes should be set in lowercase, superscript letters, immediately to the right of the pertinent data. The footnotes themselves should appear below the table, after the Table Notes (if any). Table footnotes should begin anew with each new table. If a table has been previously published, the author is required to submit a copy of a **letter of permission** from the copyright holder, and must acknowledge the source of the table in the manuscript's reference section. Running heads and page numbers should continue from the footnotes.

Figures. Figures are also numbered consecutively, according to the order in which they appear in the manuscript. The convention *Figure 1, Figure 2, Figure 3*, etc. should be followed. In cases where the orientation of the figure is not obvious, the word TOP should be placed on the page, well outside the image area, to indicate how the figure should be set. If any figure has been previously published, the author is required to submit a copy of a **letter of permission** from the copyright holder, and must acknowledge the source of the figure in the manuscript's reference section. Running heads and page numbers should continue from the tables.

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Figure 1. Exemplary formatting for all figure captions.

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

Reference Examples

Journal Article, Two Authors

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

Journal Article, Three to Six Authors

Gartner, J., Larson, D. B., & Allen, G. D. (1991). 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.

REVIEW PROCESS

Manuscripts submitted to *The Journal of Nephrology Social Work* are peer-reviewed, with the byline removed, by at least two professionals in the field of renal social work. The length of the review process will vary somewhat depending on the length of the manuscript, but generally takes two to three months. *The Journal of Nephrology Social Work* reserves the right to edit all manuscripts for clarity or length. Minor changes in style and clarity are made at the discretion of the reviewers and editorial staff. Substantial changes will only be made with the primary author's approval, prior to typesetting.

AFTER ACCEPTANCE

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

- An electronic copy of the final version of the manuscript. All components of the manuscript must appear within a single word processing file, in the order listed previously. Any features that track or highlight edits should be turned off. Do not use automatic numbering functions, as these features will be lost during the file conversion process. Formatting such as Greek characters, italics, bold face, superscript and subscript, may be used, however the use of such elements must conform to the rules set forth in the APA style guide and should be applied consistently throughout the manuscript.
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- A copyright form signed by at least one of the authors.

THE JOURNAL OF
NEPHROLOGY SOCIAL WORK
Volume 28
Spring 2008

CONTENTS

Rates and Correlates of Therapy Non-Adherence in Adult Hemodialysis Patients

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This article examines the rate of non-adherence (NA) and the relationship of demographic and psychosocial variables on NA with treatment, fluid, diet and medications in adult hemodialysis patients. We used a cross-sectional, longitudinal design, and included 107 adult hemodialysis patients. NA rates were variable depending on the outcome examined. Fluid NA rate was the highest, with 40% of participants categorized into this group. Significant differences and correlations were found between race and albumin, months on dialysis and Kt/V, and skipped treatments and Kt/V. No significant differences were found between sex, smoking, locus of control, depression, social support, general health, self-efficacy and co-morbid conditions. The influence of environmental factors, such as health care team and system factors, on adherence should be considered in future research.

INTRODUCTION

In-center hemodialysis (HD) is the most common End Stage Renal Disease therapy, as the disease (ESRD) has progressively increased in prevalence in the United States (U.S. Renal Data System, 2007). Rates of non-adherence (NA) to HD ranging from 2 to 80% have been documented (Bame et al., 1993; Leggat et al., 1998). Adherence is defined as "the extent to which a person's behavior (taking medications, following a recommended diet and/or executing life-style changes) corresponds with the *agreed* recommendations of a health care provider" (Sabate, 2003). Adherence to HD therapy requires complex, lifelong behaviors related to dialysis treatment, fluids, diet and medications. Successful adherence is critical for maintaining health, decreasing disease symptoms and preventing negative patient outcomes, such as hospitalization and mortality (Bame et al., 1993; Chan & Greene, 1994; Saran et al., 2003). The purposes of this study were to describe the rate of NA with dialysis treatment, fluids, diet and medications in adult HD patients and examine the relationship of demographic and psychosocial variables to NA with dialysis treatment, fluids, diet and medications in adult HD patients.

METHODS

Design

Using a cross-sectional longitudinal design, we drew a random sample of 149 HD patients from 6 outpatient HD centers in the Midwest region of the United States. The following criteria were used for inclusion: 21 years of age or older, receiving HD for at least 6 months, able to speak and read English and cognitively intact as defined by a score of 24 and above on the Mini-Mental Status Exam. Those with a guardian or durable power of attorney, which indicate cognitive deficits, were excluded. Dialysis nurses initially obtained permission from the patient for the research nurse to discuss the study. If permission was granted, a research nurse with dialysis experience and training in the data collection protocol discussed the study with potential participants. We randomly selected a sample of 149 potential participants from the available pool. Of the 149, 11% (*n* = 17) were either deceased or did not meet eligibility criteria. Of the remaining 132 eligible potential participants, 113 participants agreed to participate in the study, representing an 86% consent rate. Of the 113 participants who consented, 6 participants were lost to attrition due to death, transfer to another facility or change in dialysis modality. The final analyses were completed on 107 participants. A summary of sample demographic characteristics are delineated in Table 1. Co-morbid conditions were obtained from the participants' medical records. The most prevalent co-morbid condition was hypertension (*n* = 92; 73%), followed by diabetes (*n* = 57; 45%), congestive heart failure (*n* = 46; 37%), peripheral vascular disease (*n* = 17; 14%), cerebrovascular disease (*n* = 15; 12%) and chronic obstructive disease (*n* = 10; 8%).

This study was supported by a grant from the National Kidney Foundation.

Table 1

Demographic Characteristics of the Sample (n = 107)

Demographic factor	Demographic detail	*n**	Percent**
Age	Mean 54.38 years; SD = 16.83; range, 20–85 years		
Months on dialysis	Mean 51.12 months; SD = 54.07 ; range, 6–288 months		
Sex	Male	56	52
	Female	51	48
Education level	High school/some high school	62	58
	Some college/college graduate	38	36
Ethnicity	Caucasian	67	63
	African American	37	35
	Other/missing	3	2
Marital status	Divorced/never married/widowed	55	52
	Married	52	48
Employment status	Disabled/retired	56	52
	Retired due to age/preference	32	30
	Employed full/part time/other	19	18
Co-morbid conditions	Mean = 2.56 (SD ± 1.51; range, 0–8)		
Depression score	Mean = 11.42 (SD ± 8.86; range, 0–41)		

***May not always total 107 due to missing data.**
****May not always total 100% due to missing data.**

Instruments

Participants were asked to complete a series of psychosocial surveys to determine the psychosocial factors correlated with NA. The unit of analysis for all instruments was the individual. The 18-item Multidimensional Health Locus of Control (MHLC) Scale-Form C was used to measure the expectancies for internal-versus-external control beliefs. People with an internal locus of control believe that their own actions determine the rewards that they obtain, while those with an external locus of control believe that their own behavior does not impact rewards and that rewards in life are generally outside of their control. Three concepts of internal, chance and doctors/other people are measured with 6 questions each. Psychometrics have been established in the dialysis population with Cronbach alphas in the 0.60 to 0.75 range and test-retest reliability coefficients ranging from 0.60 to 0.70 (Wallston et al., 1976).

Depression was measured using the Beck Depression Inventory (BDI; Beck et al., 1961). This 21-item self-administered, self-report scale addresses mood, pessimism, sense of failure, lack of satisfaction, guilty feeling, sense of punishment, self-hate, self-accusation, self-punitive wishes, crying spells, irritability, social withdrawal, indecisiveness, body image, work inhibition, sleep disturbance, fatigability, loss of appetite, weight loss, somatic preoccupation and loss of libido. The BDI has high internal consistency with ranges from 0.73 to 0.92 with a mean of 0.86 (Beck et al., 1961). The BDI has a split-half reliability co-efficient of 0.93 (Beck et al., 1961).

Medication self-efficacy was measured using the Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES), developed specifically for renal transplant patients (De Geest et al., 1994). This 27-item self-administered, self-report scale measures confidence in taking immunosuppressive medications. It was effectively used with other chronic illness populations with good validity. The tool was modified with permission from the developers to measure long-term medication self-efficacy related to HD therapy. The question specific to immunosuppressive medication side effects, "Taking my medication even if it causes spots and excessive hair growth," was changed to "Taking my medication even if it causes side effects." The question specific to every other day dosing of steroids, common in transplantation, was removed (e.g., "Taking my medication even if it is prescribed to be taken every other day.") The tool addresses side effects, physical discomfort, emotional distress, distraction and being observed. Internal consistency reliability has been reported to be 0.94 (De Geest et al., 1995). Construct validity was determined with a median explained variance of 6% and area under the Receiver Operating Characteristic curve of 0.67 (Denhaerynck et al., 2003).

Social support was measured using the Social Support Appraisals Index (SSAI; Vaux, 1988). This is 23-item self-administered, self-report scale measures the degree of feeling cared for, respected and involved with family and friends (Vaux, 1988). The scale had good internal reliability with alpha scores ranging from 0.80 to 0.90 (Vaux et al., 1986). Stability was established with reliability scores of 0.80 (Vaux et al., 1986). Convergent validity has been demonstrated with significant associations to seven other appraisal measures (Vaux, 1988). Moreover, adequate concurrent and divergent validity with other perceived support measures was demonstrated and showed predicted associations with support network resources and psychological well-being (Vaux, 1988).

The Medical Outcomes Study (MOS) 36-item Short Form Health Survey (SF-36) was used to measure health status. The profile assesses 8 concepts, including physical activities, social activities, role limitations due to physical health, bodily pain, general mental health, role limitations due to mental health, vitality and general health perceptions. The median reliability coefficients for each of the eight scales was 0.80 or higher, except for social function, which had a median reliability across studies of 0.76 (Ware et al., 1993).

The Dialysis Diet and Fluid Questionnaire (DDFQ) was used to obtain the patient's perspective of diet and fluid adherence. The tool was designed and validated in Flanders, Belgium, to evaluate HD patients' NA behavior (Vlaminck et al., 2001). The DDFQ is a self-report instrument consisting of 4 subscales: 2 regarding NA to diet (frequency and intensity) and 2 about fluids (frequency and intensity). The intensity of NA is scored on a Likert-type scale from "no" to "very severe" deviation (Kugler et al., 2005).

Outcome Data

The outcome data, including missed or shortened dialysis treatments, Kt/V, IDWG, serum phosphorus, serum calcium and serum albumin, were extracted from the dialysis medical records for 6 months after the participants' completion of the psychosocial instruments.

The outcome measures represent the following adherence parameters: treatment adherence measured by missed or shortened treatments and Kt/V, fluid adherence measured by IDWG, medication adherence measured by serum phosphorus and diet adherence measured by

Table 2

Adherence Outcome Parameters

Measure	Good	Moderate	Poor
Kt/V	>1.3	1.0 to 1.3	<1.0
IDWG	<2.0 kg	2.0 to 3.0 kg	>3.0 kg
Serum phosphorus	3.5 to 5.0 mg/dL	2.0 to <3.5 mg/dL or >5.0 to 6.5 mg/dL	>6.5 or <2.0 mg/dL
Serum albumin	>3.0 g/dL	3.0 to 4.0 g/dL	<3.0 g/dL
Serum calcium	8.4 to 9.5 mg/dL	7.3 to <8.4 mg/dL or >9.5 to 10.4 mg/dL	<7.3 or >10.4 mg/dL

serum albumin and serum calcium. The Kidney Disease Outcomes Quality Initiative (KDOQI) standards parameters were used to guide adherence ranges. The adherence categories are listed in Table 2.

Procedure

Institutional review board and dialysis center approval were obtained prior to initiation of the study. Once a participant consented to the study, a trained research assistant administered the following scales while the participant received dialysis: the BDI, MHLC Scale-Form C, the MOS SF-36, the LTMBSES, the SSAI and the DDFQ. If participants' preferred, the surveys were read to them. The surveys took an average of about 60 minutes to complete. Following completion of the surveys, the following outcome data were extracted from each participant's medical record monthly for a total of 6 months: missed or shortened dialysis treatments, Kt/V, IDWG, serum phosphorus, serum calcium and serum albumin.

Data Analysis

Descriptive statistics including means, standard deviations and ranges for continuous variables and percentages for categorical variables were calculated. The Wilcoxon Rank Sum test was used for analyzing nominal variables. Spearman correlations were calculated due to the ordinal nature of the majority of the other variables. A conservative alpha level of 0.005 was used because 70 to 75 correlations were considered. Using a traditional alpha level of 0.05 would have likely resulted in finding significant correlations due to chance alone because of the large number of correlations calculated in the study.

RESULTS

The rate of treatment adherence included 42% (*n* = 45) of participants who attended all HD treatments over the 6-month tracking period, 30% (*n* = 32) who skipped one, 11% (*n* = 12) who skipped two and 17% (*n* = 18) who skipped three or more treatments. Shortened HD treatments showed a similar pattern with 52% (*n* = 56) of participants adherent with all HD treatments, 18% (*n* = 19) shortening one, 9% (*n* = 10) shortening two and 20% (*n* = 21) shortening three or more times in the 6-month period. The mean Kt/V for the group (*n* = 106) was 1.31 (SD = 0.223; range 0.74–2.05). Using the good, moderate and poor adherence Kt/V categories to classify individual adherence levels over 6 months, 59% (*n* = 63) were classified as good adherers, 34% (*n* = 36) were moderate adherers and 6% (*n* = 7) were poor adherers.

The mean IDWG was 2.68 kg (SD = 1.14; range –0.37–6.06). When the IDWG adherence categories were used to determine poor, moderate and good adherence over the 6-month period, 29% (*n* = 31) were classified as good adherers, 30% (*n* = 32) as moderate adherers and 40% (*n* = 43) as poor adherers.

The mean serum phosphorus was 5.73 mg/dL (SD = 1.51; range 3.04–12.30). Using the serum phosphorus criteria as a classification, 32% (*n* = 34) were good adherers, 43% (*n* = 46) were moderate adherers and 25% (*n* = 27) were poor adherers over the 6-month period. The mean serum albumin was 3.82 g/dL (SD = 0.31; range 2.82–4.59). There were 24% (*n* = 25) classified as good adherers, 75% (*n* = 79) as moderate adherers and 2% (*n* = 2) as poor adherers. Mean serum calcium was 9.05 mg/dL (SD = 0.63; range 7.49–10.50). Sixty percent (*n* = 64) were good adherers and 40% (*n* = 43) were moderate adherers. There were no poor adherers using calcium as an outcome.

Significant differences were found between race and albumin ($p = 0.004$) with caucasians having lower mean serum albumin levels (3.77 versus 3.94 g/dL for African Americans). No significant differences were found between health locus of control, gender or smoking and the outcomes. Significant correlations were found between months on dialysis and Kt/V ($r = 0.325$; $p = 0.0012$) and skipped treatments and Kt/V ($r = –0.371$; $p < 0.0001$). These correlations indicate that those with longer length of time since initiating dialysis had higher Kt/V values and those who skipped more treatments had lower Kt/V values. No correlations were found between depression, social support, general health score from the MOS SF-36, self-efficacy or number of co-morbid conditions and the outcomes. The mean depression score for this sample indicates minimal depression levels in the group.

DISCUSSION

The results of this study indicate that rates of NA in this sample of adult HD patients are variable depending on the outcome examined. The majority of participants were categorized as having good adherence when skipped treatments, shortened treatments, Kt/V and calcium were explored. However, when adherence to serum phosphorus and serum albumin parameters were assessed, most participants (75% in both groups) were classified as only moderately adherent. NA to fluid restrictions, measured by IDWG >3.0 kg, showed the highest NA, with 40% of participants categorized into this group. Comparison of results with other published studies is difficult due to varied operational definitions of adherence outcomes (Russell et al., 2007). Future use of KDOQI guidelines for measuring adherence parameters will certainly minimize this comparison barrier.

The mean Kt/V was 1.3 for all patients, suggesting that most patients had adequate HD. Only 6 out of the 107 patients had Kt/V <1.0. Presently, greater efforts are made to maintain better clearances for patients. By today's standards, poor Kt/V values <1.0 would have been adequate values years ago. In this study, adherence may have little effect on Kt/V, as nephrologists have many more ways to manage non-adherent patients through increasing the number of sessions, dialysis time, dialysis frequency (e.g., nocturnal home HD) or reducing flow pressure.

The difference in NA outcomes between Caucasians and African Americans is generally not supported by other studies (Russell et al., 2007). Only one study found that serum albumin significantly contributed to predicting patients' diet adherence behaviors ($b = 0.102$; $p = 0.003$) but did not examine race differences (Zrinyi et al., 2003).

The statistically significant positive correlation between length of time since initiating dialysis and NA found in this study has been documented by about 30% of other studies (7 of 27) (Russell et al., 2007). However, the opposite has also been found—that shorter time on dialysis is statistically significantly correlated with NA. Other confounding factors, not yet explored, must be involved to explain this wide variability in results.

The correlation found between skipped treatments and Kt/V is consistent with our understanding of dialysis therapy. If patients skip treatments, they will not receive adequate dialysis therapy, resulting in lower Kt/V levels. The finding that those who had been on dialysis longer had higher Kt/V levels is also expected. Those who did not have adequate dialysis might have been more likely to die and were not included in the study (Lowrie & Lew, 1990).

A significant finding of this study is that many of the hypothesized predictor variables were indeed not significantly correlated with NA. Sex, smoking, depression, health locus of control, social support, general health score from the MOS SF-36, self-efficacy and number of co-morbid conditions were not correlated with treatment, fluid, diet or medication NA.

As with all research studies, there were several limitations of this work. Generalization to other areas of the United States and beyond is cautioned because the sample was drawn from a rather limited geographic region. Additionally, the resulting sample was small. However, inclusion of only one predictor variable for every 10 participants in the total sample when conducting the analysis minimizes concern. Although the consent rate was quite high, there is a possibility that those who chose not to participate may be different than those who consented to the study. For example, more NA individuals may have decided not to participate. Another possible limitation is that participants may have provided socially desirable answers to the survey questions. However, an attempt to address this threat to internal validity was made by using a trained research assistant to administer the surveys and not the dialysis staff members.

FUTURE RESEARCH

The present study's findings, when placed in the context of mixed findings from other published literature, suggest that other influences must be examined in future adherence research in adult HD patients (Hailey & Moss, 2000; Hoover, 1989; Morgan, 2000). The World Health Organization, in a 2003 landmark evidence-based report on adherence in chronic illness, emphasized that adherence to medical therapy is influenced by a multitude of factors (Sabate, 2003). These factors include social and economic, health care system, health care team, disease/disease therapy and patient-related factors. The report also stresses that health care providers and researchers continue to focus on patient-related factors for remedying adherence problems, when factors in the patient's environment, such as health care team and health care system, may have an even greater influence. If adherence is to be improved, each of these factors must be addressed in future research studies.

IMPLICATIONS FOR PRACTICE

This study's findings support prior research in that adherence to HD medical regimens is a problem in the adult population and that patient-related factors as predictors for adherence are not robust. As such, health care providers must utilize the broader adherence evidence for practice guidance until results are available from the adult HD population. The adherence evidence suggests that adherence-enhancing interventions must be designed for each patient based on routine assessment of individual needs, as no one intervention or groups of interventions have been effective (Haynes et al., 2005; Roter et al., 1998; Sabate, 2003). Utilizing the clinical assessment and intervention skills of the dialysis center's qualified social worker is critical. Adherence assessment and support must be an ongoing process because adherence behavior occurs in a person's dynamic and changing environment (Sabate, 2003). Health care professionals can provide helpful support to patients, yet little training on adherence has been integrated into health care preparation and continuing education (Sabate, 2003). Consequently, intervention programs addressing information about adherence, clinical decision-making processes and the use of behavioral tools are greatly needed both in the practice and health care education systems (Sabate, 2003). Those based on individual needs, family, community and patient organizations can be important in supporting adherence (Sabate, 2003). Finally, multidisciplinary teams must collaborate to enhance adherence (Sabate, 2003). Collaboration should occur at the patient, peer, health care professional, dialysis unit and health care delivery system level.

CONCLUSION

Adherence to medical therapies by adult HD patients continues to challenge health care professionals. Demographic and patient psychosocial factors are not strong predictors. Health care providers must use adherence evidence from the broader chronic illness research in practice. Nephrology social workers are able to utilize their training and skills related to psychosocial assessment to determine barriers and risks for each individual patient upon initiation of dialysis, as well as on an ongoing basis. Future research must focus beyond adherence influencing patient factors and instead explore adherence influencing health care team, system and social and economic factors.

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Relationships in Transition: Young Couples Facing Renal Failure and Transplant

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Young people are not the typical population one might imagine when thinking of chronic illness, yet many young people encounter major health issues. The current literature neglects to adequately examine the impact serious health concerns might have on young couples. This study seeks to examine the impact of End Stage Renal Disease (ESRD) and its treatments on relationships between the ill spouse and partner. In an exploratory, phenomenological fashion, six couples shared details of their experiences with ESRD and its impact on their relationships. This research presents a complex picture of the disease experience itself, and indicates that the experience of illness is not always negative for couples. The conclusion contains suggestions for those working with couples facing ESRD.

END STAGE RENAL DISEASE

According to the National Kidney Foundation (NKF, 2001), chronic kidney disease is the ninth leading cause of death in the United States. The two most common treatments for End Stage Renal Disease (ESRD) are dialysis and kidney transplantation. Of the 345,000 Americans being treated for kidney failure, 100,000 of those are currently living with a functioning kidney transplant, while the remaining 245,000 are receiving dialysis treatment.

FROM DIALYSIS TO TRANSPLANT

Unlike individuals waiting for other transplantable organs (e.g., hearts, lungs), patients with ESRD are not as likely to die from their disease because artificial means of filtering bodily waste (i.e., dialysis) are available. However, dialysis is uncomfortable, time-consuming and changes a patient's life and self-image in many ways. Shulman et al. (1987) reported that nearly 40% of patients receiving dialysis were diagnosable as clinically depressed, yet were rarely treated. Yeun and Depner (2000) noted that common responses to dialysis include denial, anger and negative attitudes toward renal replacement therapy, and these responses are often most intense in younger patients. Devins et al. (1997a) found that maintenance dialysis provided patients with a limited opportunity for high quality of life compared with patients with renal transplants.

For dialysis patients awaiting transplant, the delay between being placed on a donor list and receiving an organ is often many years; the screening process is strict, and tests can last for months or years. While on dialysis; patients must carry pagers or find other ways to maintain constant contact with the transplant center. Travel must be restricted due to the difficulty of arranging for and finding dialysis in different areas of the country. Dialysis patients often spend up to 20 hours per week in treatment-related activities; these time constraints, health concerns and freedom restrictions not only take a toll on the patient, but also significantly impact the patient's relationships and loved ones. Artinian (1990) reports that patients undergoing dialysis complain about being treated like a child; having reduced responsibilities, capabilities or trust; and feeling a lack of support. He also suggests that the "sick" partner has no choice about his or her lifestyle or role while undergoing dialysis treatment, in contrast to the "well" partner.

Following a renal transplant, the fear of organ rejection eliminates a feeling of complete health and well-being, and the anti-rejection medications come with their own unappealing side effects (Kong & Molassiotis, 1999; Viswanathan, 1991). In fact, Kong and Molassiotis found that life after a renal transplant is often marked by a fear of rejection, difficulties complying with medication regimens, fear of infection, financial concerns and uncertainty about the future.

However, according to Koch and Muthny (1990), kidney transplant is preferable to dialysis in many areas of post-surgical functioning. They noted that patients who received a successful renal transplant reported more positive functioning in the areas of health, work and emotional well-being than those patients who remained on long-term dialysis. Christensen et al. (2000) found that levels of depression were substantially lower for those who actively sought out health information following their transplant. Rudman et al. (1995) found that patients who complied with their medical regimen post-transplant were more likely to rank satisfaction with life and health high. Zumbrunnen et al. (1989)

Study conducted through Colorado State University, Department of Psychology, Fort Collins, CO.

found that although patients experienced fears of their bodies rejecting the new kidney, they also experienced great relief at being free of their reliance on a cumbersome machine for their survival, leading to a dramatic improvement in their overall quality of life.

GOALS OF THE CURRENT STUDY

This study seeks to examine the effect upon a relationship when one member of the couple received a kidney transplant after experiencing the diagnosis of ESRD and its treatments. Of particular interest, as noted, is the effect upon relatively young couples, who statistically and socially would not be expected to deal with such a dramatic, traumatic event so early in their lives and relationships. Given the relative dearth of information within this area, the present study focuses on gathering a full picture of each spouse's experiences and viewpoints on changes within the relationship using a phenomenological interview process. The research focuses on both partners' impressions and experiences, from diagnosis to post-transplant, social and family relationships, sexuality, communication, division of labor and overall relationship well-being.

Social Issues

Much of the research on ESRD, dialysis and transplant focuses on the physical and medical issues faced by renal patients. Unfortunately, this research often neglects to address the patient's social environment and relationships. The experience of a chronic or long-term illness such as ESRD takes a toll not only on the well-being of the patient, but also on those people with whom the patient has significant relationships. Spouses, particularly, are impacted tremendously when their partner is diagnosed with a serious health problem (Conley et al., 1981; Revenson, 1994; Smith et al., 1986).

Impact on Spousal Relationships

Helgeson (1993) found that, in most marital relationships composed of two healthy individuals, spouses alternate between providing and receiving support, as needed. However, at least in the initial adjustment to illness, the patient is far more likely to be the one receiving support and the spouse is more likely to be providing the support. While this makes sense when one spouse becomes ill, it can result in stress and lack of support for the healthy spouse. In addition, Carter and Carter (1994) noted that spouses of the chronically ill tend to report that the illness created more negative effects on the marriage than did the spouse who was diagnosed with the chronic medical condition. The negative emotional impact and feelings related to the intrusion of the illness into the marital relationship tend to be shared by both partners (Gritz et al., 1990).

Because it is widely recognized that when a married person is ill, it is their spouse who serves as his/her main source of support (Conley et al., 1981; Revenson, 1994; Smith et al., 1986), it is essential to facilitate a healthy, strong relationship between spouses to enhance the well-being of this primary relationship and the patient. Kalayjian (1989) noted that spouses of an ill partner often report their own feelings of depression, loneliness and helplessness. Davis-Ali et al. (1993) noted that there was significantly more social support available to the patient than to the "well" spouse. The well spouse may report feelings of resentment or anger related to the time, energy and attention focused on the patient (Wilber, 1988; Williamson et al., 1998). As it is often considered to be culturally unacceptable to express negative emotions about a loved one who is ill, these feelings of anger and resentment are likely to turn to guilt (Oberst & James, 1985).

Rolland (1994) noted that couples who are faced with long-term health issues are often greatly challenged when it comes to developing and maintaining healthy communication skills. Farkas (1980) examined relationships in which one spouse was experiencing a chronic illness and discovered that many wives of men with chronic illnesses may tend to disregard their own physical and emotional needs in order to more fully focus their attention on or care for their husbands. Many of these women were unable or unwilling to change their behaviors. Wilson (1991) suggests that men may perform similar behaviors when their wives are ill, and noted that husbands often engage in "buffering," or attempting to filter information to provide a shield from the potential pain and suffering their wives might experience if they knew how difficult or serious the situation really was. Davis-Ali et al. (1993) found that "well" spouses tend to worry more about the patient's future than the patient. Spouses of the chronically ill may also wish to minimize the health problems of their partners in order to promote optimism or an image of health to the outside world. Heijmans et al. (1999) found that, however unintentionally, this may give their ill spouse the impression of not being taken seriously and damage the relationship.

Impact on Sexuality

Glass et al. (1987) found that there were significant differences between the sexual functioning of dialysis and transplant patients. They found that dialysis patients reported a lower frequency of sexual intercourse, and men undergoing dialysis reported more difficulties gaining and maintaining erections than men who received kidney transplants. In addition, they reported that more marital difficulties in general were reported by participants who were undergoing dialysis than those who had received transplants.

Coping With Stress

Hope and optimism, particularly, are factors that may be impacted uniquely by couples facing ESRD, as the prospect of transplant is often far on the horizon. While a kidney transplant is not a cure for ESRD, but instead a treatment that must be continually monitored and cared for, it is still far less intrusive into one's life than dialysis. Frazier et al. (1995) reported that while ESRD patients experienced higher overall levels of stress, spouses were equally or more stressed than the patients on some issues. In addition, they found that patients reported more depression than spouses, and that spouses who reported less personal stress were more helpful to their recovering spouse.

Rolland (1994) suggested that couples are often so shocked or terrified when they receive the initial diagnosis of a serious illness that they react either by pulling away from each other or clinging together in a fused manner. Parker (1993) presents a more positive light on chronic illness and disability within a marriage, citing that while all couples noted some negative impacts on their lives together, many of those same couples believed that the shared experience actually brought them closer together as a couple and strengthened their relationship. In a similar vein, Rait et al. (1989) noted that many couples use the experience of a long-term illness in a positive manner, establishing better communication skills and learning to value every moment with each other as life partners.

However, much of the research on the effects of chronic illness within a marital relationship focuses on couples in middle-adulthood and beyond (Devins et al., 1997b; Parker, 1993). This makes sense, given the demographic occurrence of chronic illness within the United States (Centers for Disease Control and Prevention, 1996), chronic illnesses tend to occur in older populations. What happens when a chronic illness affects a younger population?

IMPACT OF CHRONIC ILLNESS ON YOUNG MARRIAGES

What might one expect to happen when long-term illness strikes a young relationship, when a healthy sense of mutual support may not have had a chance to fully develop? Relatively young spouses who promise themselves to one another "in sickness and in health" rarely expect a life-threatening disease to test that promise. "Immature" couples, who are either not capable of or are unskilled at providing mutual support and nurturance, were noted by Peteet and Greenberg (1995) to be at greatly increased risk for marital distress and difficulty due to long-term illness.

Artinian (1990) found that many young couples did not handle the dependency issues or the uncertainty well. She noted that many of the marital difficulties stemmed from resentment over extra work on the part of the well spouse or worry about the survival of the spouse undergoing dialysis treatment. Artinian explored the question of ESRD with young couples and found that many couples consider divorce or do divorce in the face of such uncertainty and stress.

Revenson (1994) noted that spouses of chronically ill partners have a dual role: that of primary provider of support to their partner and that of a family member who also needs support in coping with the illness of a loved one. Obviously, both spouses are greatly impacted by the introduction of a chronic illness into their marital relationship. However, in these studies, the methodological approach fails to address the relationship itself. How do their interactions change? How does sexuality within the marriage change? How do involvements with the outside world change and impact the marital relationship? How is hope for the future affected as these couples move through young adulthood coping with a chronic illness that may be foreign to their original expectations?

Peven and Shulman (1999) state that early in a marriage, an erotic attraction is necessary to facilitate a healthy relationship. This presents an obvious difficulty for young couples in which one member is too ill to fulfill the physical demands of that attraction. The exhaustion of dialysis, coupled with the inevitable, unpredictable health issues that will arise with ESRD, may affect the physical and emotional energy of both members of the couple, thus challenging them in this most basic element of any relationship. Hooper's (1994) research found that younger patients without spouses often tended to cease sexual activity until they received a transplant.

Young Lives on Hold

Rolland (1994) suggested that young couples are impacted greatly because most of their dreams, both individually and as a couple, have yet to be realized. He noted that many couples reported "an acute sense of loss or being robbed" (p. 330). In addition, he reported that these couples are somewhat out of sync with their peers, as most other young couples are not facing chronic health issues and thus are more likely to become socially isolated and feel disconnected from their peer groups.

Examining the Shift From Dialysis to Transplant

Following a renal transplant, the fear of organ rejection eliminates a feeling of complete health and well-being, and the anti-rejection medications come with their own unappealing side effects (Kong & Molassiotis, 1999; Viswanathan, 1992). In fact, Kong and Molassiotis found that life after a renal transplant is often marked by a fear of rejection, difficulties complying with medication regimens, fear of infection, financial concerns and uncertainty about the future.

As previously noted, young patients tend to qualify for renal transplantation, and can be placed on transplant lists waiting for non-living donors or find friends or relatives willing to attempt living donation. How does the surgery, or even the prospect of this surgery, affect the relationship between young spouses? The surgery and related events are expensive, and patients and their spouses are often faced with unbearable financial burdens. This could be especially troublesome for young couples. Horowitz et al. (1998) found that financial need is associated with more problematic and less supportive partner relationships in young couples.

In addition, the transition between dialysis and post-transplant life is a major shift in lifestyle for most couples. What impact does it have to go from a debilitating and time-consuming treatment to a life post-transplant, when one's illness no longer functions as the major focus of one's day? Young couples who have faced dialysis and major surgery must face yet another major change within the young relationship.

Helgeson (1993) found, that after the initial impact of a chronic illness on a marital relationship was over, most spouses reported that their boundaries and roles were back to pre-illness levels. But Helgeson found that the well spouse continued to provide more support and received less support and help than prior to the illness. Schover et al. (1990) noted somewhat similar findings in that levels of sexual desire increased significantly post-transplant, but sexual activity and overall sexual satisfaction remained relatively unchanged 3 years following the transplant. In contrast, Abram et al. (1975) reported that 40% of the men they studied who received a kidney transplant noted an increase in sexual potency after the transplant. But these findings omit actual examination of the interpersonal aspects of marriages themselves.

FOCUS OF THIS STUDY

As noted, the relatively limited research addressing young couples facing ESRD and transplant makes this an area much in need of research. The present study attempts to address some of the gaps in research by using a phenomenological, qualitative approach to examining the experiences of several young couples who have faced ESRD together.

METHODOLOGY

The Phenomenological Method

Creswell (1998) describes the phenomenological method as one that enables the researcher to focus on the lived experiences of the individuals being studied. To avoid biasing both the responses of participants and the later analysis of those responses, questions were phrased in an open-ended, non-judgmental fashion to eliminate the expectation of a particular response bias. Questions examined the partners' experiences from pre-diagnosis of ESRD, through diagnosis, dialysis and other treatments to the relationship, post-renal transplant. Responses to oral interviews and written questionnaires were summarized and reflected back to the participants to find if there was any confusion and to allow for clarification and ensure that the interviewer understood the responses correctly.

Participants and Sampling

Participants included 6 otherwise healthy couples (comprised of 12 individuals) who had recently (within the last 10 years) experienced one partner shifting from diagnosis of ESRD to post-renal transplant. Both members of the couples were under the age of 40 at the time of transplant, and were married for at least 6 months, but no more than 10 years, prior to transplant.

Participants were given the option of in-person or written versions of data collection. One couple selected an in-person interview, the other five selected a written version. Participants were recruited from both contacts with a regional renal social worker and through posting on a NKF transplant recipient message board on the NKF Web page. There were no significant demographic differences between the interviewed and the surveyed couples.

Data Collection and Analysis

Within the oral interview couple, each partner participated in a confidential, audiotaped interview with a research assistant who asked broad questions about each research area. If participants chose to complete a written version of the interview instead of an oral interview, the questionnaires were collected, transcribed or retyped from their original format to ensure accurate and adequate data analysis and assure confidentiality. The questions for each method were identical. The participants were asked to respond to questions in the format of the following: “What changes, if any, did you notice in your life and relationship regarding the area of [sexual intimacy]?” Each area of inquiry was denoted in a separate question, similarly phrased. Data was analyzed in several stages, according to the recommendations of Creswell (1998), Moustakas (1994) and Patton (1990). The researcher identified and integrated major themes into a narrative description of the lived experience of ESRD and the treatments for it, namely the transition from diagnosis to post-transplant and its impact upon marital relationships. The themes that emerged from the analysis of these interviews were then summarized within the context of the five original research areas: communication, sexuality, social and family relationships, division of labor and overall relationship well-being.

INTRODUCTION TO THE PARTICIPANTS

Participating Couples

Ann and Brian have been married for 10 years. Ann was unexpectedly diagnosed with ESRD less than 2 years prior to the study, and she started dialysis approximately 1 year later. She and Brian worked together to establish a life around her dialysis treatments, and Ann received a kidney from a family member 5 months later. They participated in the study just 3 months after Ann’s transplant. Both spouses were currently healthy at the time of the study, and they completed a written version of the interview. Brian was 36 years old and Ann was 34 years old as they completed the questionnaire.

Carol and David have been married for 3.5 years. Carol was diagnosed with ESRD just 2 years after they were married, and although dialysis was not required, she did receive a kidney from a non-living donor just 1 year after her diagnosis. Carol received her kidney transplant approximately 7 months prior to participation in the study. Both spouses were healthy at the time of the study, although Carol had recently suffered a broken limb. At the time of their participation in the study, Carol was 30 years old and Brian was 34 years old. Carol and David completed the written version of the interview.

Erica and Frank have been married for 4 years. Frank was diagnosed with ESRD just 6 months after their wedding, and they coped with dialysis as a couple for approximately 16 months, starting 5 months after his diagnosis. At the end of that time, Frank received a donated kidney from a family friend. Both spouses were healthy at the time of the study. At the time of their participation in the written version of the interview, Erica was 30 years old and Frank was 33 years old.

Gail and Heath have been married for 14 years. Five years ago, Heath was diagnosed with ESRD and underwent dialysis treatments for just 1 month before receiving a kidney from Gail. Both spouses were healthy at the time of the study, although Heath was suffering from some mild heart problems. At the time of their participation in the written version of the interview questions, Gail was 38 years old and Heath was 40 years old.

Iris and John have been married for 8 years. Iris was diagnosed with ESRD 2 years prior to their interview following a long history of diabetes. She received dialysis treatments for 7 weeks before obtaining a kidney transplant from a friend of the family. Both she and John were quite healthy at the time of their participation. Iris and John were interviewed in person, and were 32 and 33 years old respectively, at the time of their interviews.

Kathy and Louis have been married for 4 years. Louis was diagnosed with ESRD 2 years after they were married, and he received in-home dialysis for 2 years before receiving a kidney transplant from Kathy 6 months prior to their participation in the written version of the interview. Both Kathy, 34, and Louis, 37, were healthy at the time of their participation.

FINDINGS

Analysis of Themes

As the researcher examined the commentaries and qualitative data provided by the 6 couples interviewed, several fundamental themes and issues emerged. Partners discussed the specific topics addressed in the interview questions: communication, sexuality, social interactions, division of labor and overall satisfaction within marriage. Other topics that emerged were fears for the future, financial concerns and worries about the impact of the disease on their children. Sexuality in the face of medical intervention was discussed candidly, and many couples noted improvements after the transplant in this arena. It is worth noting that the only factor universally noted by couples was a sense of optimism and gain from the experience.

Improved Connections with and Reliance on Outside Support Systems

The experience of ESRD, both the physical aspects of the disease and the practical aspects of its treatments, is exhausting, and reliance on friends and family during times of need was essential to surviving the experience. The couples described receiving meals, child care, transportation, dog-sitting and some even noted friends or family who helped clean the house or sat with the ill spouse for support when she or he was unable to socialize in his or her normal fashion:

> My two girlfriends became my confidantes, listened to me ... during the whole crying and being scared, and John turned towards the guys in the group, and he shared more with them about what he was feeling, his fears, etc. (Iris)

Sometimes a neutral party felt safer to share with than did a spouse; friends created a support network the couples knew they could lean on.

> We had some friends in the neighborhood that would drop by, (would) bring us a meal without us asking for it. They'd ask if they could help and we'd tell them 'no,' but they'd keep bringing us food and stuff. (John)
>
> Close friends were amazing about bringing meals and caring for our pets when my husband would be in and out of the hospital, and it meant the world to us to have that support. My family helped us out financially and by coming to visit and help(ed) out during the transplant, and friends did fundraisers and called just to offer groceries if they were out shopping or (offered) other support when they could. (Erica)
>
> We are very fortunate to have a good friend who has been an angel to us. She has helped with watching our son when I had to go to the doctor's or if I was in the hospital. She organized people to bring dinners over on certain nights, etc. (Ann)

In addition to practical support, emotional connections between the couples and their friends and family were improved as well. Ann noted: "I started going to church more when I got sick, and met some truly wonderful people. I think I have become a much more open person." Frank reported a stronger connection with friends, stating:

> I think we both really appreciate close friends and family more than we did before. I don't think we knew how much support we had until it was tested by this experience…I thank God we had it or I don't know how we could have made it!

Carol indicated, "I think I'm more social now than I ever was before," and her husband David concurred: "I think my wife's illness has actually helped us grow closer to our family and some of our friends."

Erica and Frank learned to spend quality time with people whom they trusted and loved, and with whom they felt a true bond:

> I think we lost a lot of acquaintances through the process, but learned a lot about what really matters in relationships and friendships … I spent less time with people from work and more time with just my husband and close friends … I think we both really liked the shift from less "superficial bonds" trimmed down to real connections. (Erica)

Improved Communication Between Spouses

In 8 of 12 interviews, the partners mentioned an improvement in communication as a result of their mutual experiences with ESRD and renal transplant, and felt that they had not only been tested by the experience, but had passed a test. They felt it had strengthened them, were proud of how they handled it, and were glad they had been given the opportunity to prove their commitment to one another in this manner.

Ann noted several small changes:

> I think my husband and I have become much closer. We learned how to communicate without talking. I have learned how to ask for and accept help. My husband has been helping me to express my feelings.

Frank also noted an improvement in communication: "I am more able to share my feelings with her, and we are really good at understanding each other without a lot of explanation." Ann's husband Brian concurred:

> We learned to understand what the other was feeling and to be able to listen to each other. We talk much more than we did before. We also talk about more realistic things.

Frank and Erica also indicated a positive impact on their communication from the experience, but with a different focus.

> [W]e have gotten easier with one another and less likely to be embarrassed about sensitive topics. We have had to discuss stuff that probably isn't normal for young couples to discuss, like all the physical aspects of what kidney failure and dialysis did to my body. (Frank)
>
> We certainly learned to talk about issues that other married couples might get away with ignoring … bodily functions and feelings being number one there. We had to learn to listen to

> his doctors and still make our own decisions based on what WE wanted … After the transplant, we had to talk pretty openly about body functions still, but it was with a different perspective. It was more hopeful and less related to nausea and pain … [Th]is whole procedure has made us better about just saying what we mean and not beating around the bush. (Erica)

Kathy reported that Louis was not particularly communicative at first. She described his reticence to have her come with him to dialysis, and his lack of sharing information.

> Finally, he allowed my mom to join him for one of the visits and afterwards she gave me a [long] replay of the visit. During that conversation, Louis mentioned that he finally understood what I was interested in hearing, that he had no idea I wanted that much information. As we met with doctors together, we grew to understand each other better. Fast forward to after the transplant, and now he is able to open up more.

John reported poor communication with Iris at first, but after they were able to acknowledge the need to speak more openly, he noted:

> We certainly relaxed some … [and] shifted more to getting through to the next step, we would set benchmarks for ourselves, when we get to this point we'll be this much closer. The relationship … got better after that discussion.
>
> [After the dialysis, we have] been very thankful and very happy, very lighthearted, and that of course can improve a relationship … Our attitudes are better, our worries are less, I think we joke around more now. We did that, earlier in our marriage, but as the surgery got closer that kind of got put on the back burner for a while. So now we're back to more joking around, more laughing, more let's go out and do something, kind of more spur of the moment type things. (Iris)

By the end of her interview, Iris indicated that she and John had learned to improve their communication. However, it was a struggle for them to work through, and his communication actually seemed to be less open and less helpful to their relationship for a significant portion of their experience with ESRD.

> He didn't talk about it as much, when he did talk about it he was very passive, like everything's going to be fine, don't worry about it, you know I've been praying a lot about it, given it a lot of thought, and that's it. (Iris)

John described some of the factors that were keeping him from feeling open about communicating:

> That was part of the issue, was that "I don't want you to go to the hospital and not come back." She didn't realize how much stress that was causing me. But I was extremely confident that she was going to be just fine, I just, it's a conscious/unconscious battle. I know that she's going to be fine, but unconsciously those fears are building up. Until you bring them out into the light of day, force them out and deal with them that was what led us down the path of having the really explosive argument … I usually am rendering aid to other people and not needing it in return, and so it was real hard for me to deal with, this whole macho ego thing, "I don't need any help," so to have it hit me so closely. I try not to be egotistical about it, but I'm sure that was some of it, that male, socialization that I need to be "the man"…

He was not avoiding communication to avoid connecting with his wife, but instead out of fear of harming her or making her feel bad for causing him stress. He also reported some role conflict with who he felt he "should be" and what he was actually feeling. After the transplant was over and he could figuratively "let go" of the tension he was trying not to show, Iris found out how John reacted:

> As soon as they knew I was okay, John pretty much had this total release of all of his emotions he had had bottled up inside. He was crying on everyone's shoulders and just became very protective, very excited, I could tell that he was excited that everything had gone well, and I think he had a tremendous relief.

By not communicating openly with his wife, whether out of fear of seeming less strong and masculine, or that he could add stress to the already high burden his wife was shouldering, John had bottled up an enormous level of stress and fear that was released only when he was sure that she was going to survive.

Improved Bond or Connection Between Spouses

Many of the couples indicated that the experience of ESRD was actually beneficial to their relationships. This was the theme that emerged most often, occurring in 11 of the 12 interviews conducted. Brian expressed this sentiment as follows: "I learned just how much she means to me and just what a special person she is. In a way, I am glad we went through this. We have a stronger marriage because of this." His wife Ann concurred, stating:

> I think we are much stronger as a couple. Having to go through something like this puts a huge strain on a marriage. Brian and I learned

> just how much we really do love each other. It was very hard at times, and we easily could have given up, but we didn't. Our love survived and got a heck of a lot stronger.

Heath stated similarly: "I think the transplant brought us closer together."

Frank and Erica expressed a sense of renewed faith in their relationship and a belief that they had been tested and grown closer through this experience.

> My wife and I are closer now than we have ever been, and we can talk to each other about anything. I think that we are compatible in every way and have learned to deal with each other's quirks and insecurities on a whole new level. I know she will stand by me through anything, and I trust her completely … I do not know how I could have made it through all of this without her. We laugh that if we can make it through [this], we know we're in it for good. I think we're in it for life! (Frank)
>
> I think that, overall, our marriage has been improved by this experience. I would not wish it on ANYONE, it was not fun to go through, but ... I have no doubt that we can make it through anything together, after what we have been through already … I think the whole experience has taught us how much we value each other and our relationship and our love. In a sad, backwards sort of way, I am glad we went through it all. (Erica)

Carol and David indicated a similar sense of strength and growth. Carol said, "I know we're both stronger individually and as a couple because of the past couple of years." David said, "My wife's renal failure and transplant have definitely brought us closer together and made our marriage stronger."

Iris and John reported an increased bond within their marriage as well. Iris indicated that some of this was due to her own fears of mortality and disability, and valued his commitment:

> It was good for me to realize that if I am going to go through a hard time, he's going to be there for me … I think now I'm more confident than ever that he and I are soul mates, and we're the best of friends, and I know that I can rely on him and he knows he can rely on me. (Iris)

After the cloud of illness had been lifted from their everyday interactions:

> I think we joke around more, we laugh more, I'll pick on him more, and he's a big guy but I feel like I can hold my own and I feel stronger. It's been a real positive thing for us, not necessarily to go through, because it wasn't fun, especially all the worry and the planning and the "what ifs," but once you get past the healing and knowing that everything is on the right track, it's a wonderful feeling and you can't help but want to enjoy life again. (Iris)
>
> The growth that we've experienced because of what we were put through has certainly made our relationship stronger and more meaningful. We certainly understand each other on a deeper level than we did before. (John)

Iris described their early relationship and specifically how this experience has helped them grow from a more self-focused or idealistic phase into a more realistic, substance-focused phase:

> In the first couple of years of our marriage, it was always kind of, not real rocky, but fighting about little things. [Illness] puts life into perspective. I think in a way it was good for us, made us realize that we needed to grow up and make some priorities and figure out different goals and what we needed to do.

Kathy and Louis describe how the experiences they went through not only tightened the bond between them, but also insulated them from external influence:

> There has been a closer relationship between us as if we were connected at a different level. We are definitely more sympathetic to each other's needs … There is a connection made between the two of us that separates us from the rest of the world. The feeling is of a true bond above and beyond what we had prior to the transplant. (Louis)
>
> Overall satisfaction within our marriage is high. We have gone through so much. During dialysis, I was frustrated by the situation and Louis's lack of communication. I learned a lot of patience and after the transplant, I believe that Louis and I can get through anything. We have an impenetrable bond. (Kathy)

The difficulties they faced together, and the lessons they learned in facing those challenges, served as an impetus for relationship growth and restoration.

Sexual Intimacy

While many couples described difficulties within their sexual relationship during the preliminary diagnosis phase, dialysis, post-transplant and recovery, other couples indicated that their sexual relationships had improved.

> Somehow, even when she was in the worst stages of her renal failure, she would have a few hours or a day when she felt good and we

> would capitalize on it … Because we were able to maintain a healthy sex life throughout her illness, I think it helped us maintain a high level of emotional intimacy, which, in turn, helped us deal with the health issues we faced. (David)
>
> We talk more now [while being intimate], too, and laugh, which we didn't used to do. I think we're both more comfortable with each other and less worried about being embarrassed. (Frank)
>
> Sex in general was changed from all of this though, because … we had to learn to talk about EVERYTHING in detail without being embarrassed, so I think this actually helped in our sex life! (Erica)

Decrease in Social Connections

The stress of being "different" or of having so much chaos occurring in the lives of these couples served as a barrier between themselves and the outside world.

> I might have gotten less social during this experience because I got tired of everything that was going on in our lives and didn't have any more energy left to give away to others. I sort of "cocooned" into our families and our really close friends, and I don't think I ever branched back out … (Erica)

Negative Impacts on Life

Not all aspects of these couples' struggles with ESRD were so positive; although some of these negatives turned out to be positives. As we will see, the impact of the illness took a toll in many areas of life, from finances to housework, to sexuality and communication, and to employment and independence.

As Brian stated, "when we got married, it never occurred to either of us that something like this could happen … when it happened, it was very hard to deal with." Others agreed that they could not be sure what sort of impact the transplant really had on their relationship, because as young couples, they had not yet experienced marriage without it. They had not yet experienced "normal."

Dealing With Guilt, Anger and Resentment

Many couples noted that the ill spouse sometimes felt useless or even guilty for their lack of energy or productiveness. Some even mentioned the well spouse feeling resentful or frustrated, however briefly, at the workload that inevitably fell on their shoulders, and indicated that it was difficult to be the primary caregiver for someone who was supposed to be their equal partner:

> There were times when my wife was sick that I got a little mad about having to mow the lawn or clean the house when she was lying in bed. I never really said anything about it though, because I knew it was killing her not being able to help out. I knew how much she hated being weak and nauseous all the time. I just reminded myself that she certainly would have helped out if she could. (David)
>
> It was hard for me to know what to do for my wife. She didn't want any help, even though she really needed it. I would get mad at her for not doing something, and then she would tell me that she just couldn't do it. (Brian)

Iris also noted that as the patient, before her transplant she was not always as caring or giving as an equal partner might be expected to be:

> I probably sound like I thought I was going to die or something, and I guess of course the thought did go through my mind a couple times. But I think I did have my mind so much on "I'm going to have to go through this surgery" that I kind of forgot maybe some of the main parts about life. As far as just being, maybe being the person that he needed me to be. I'm sure that I had several selfish times when maybe I didn't give to him as much as I should have, because I was just so wrapped up in the worry of it all. Now, it's all behind us, and I can mentally be there for him for anything now, where before it was probably the other way around, like he felt like he needed to be there for me, supportive for me, now we're more meeting each other in the middle. It's been a good thing.

Financial losses were prevalent. As Ann noted: "When I got real sick, I had to quit my job of 15 years. My husband took a couple of months off of work in order to help out with everything."

> I felt very guilty about him having so much to do and still work every day at his job. My disability and Social Security definitely (had) helped financially … I wanted so desperately to be helping out in some way. (Carol)

Others also noted a change in ability to share the workload around the house.

> It was hard, because I was always on top of it, and when I was on dialysis, there were days when I just couldn't do anything … of course, there were days on your in-between days [between two dialysis treatment days] when I would actually feel better than I'd felt in a long time, because that dialysis just cleaned so many toxins out of my system … so there were some days when I felt good enough to do things so I did them. I got tired, but I took advantage of those times and would do a load

> of laundry or pull out the checkbook and pay bills or whatever … when I did feel good, I felt like I took advantage of it, and when I didn't, I just had to accept the fact that I couldn't do anything. (Iris)
>
> I know there were times when I was sick that I did pretty much nothing, and my wife took care of a lot around the house, more than her share for sure. I never heard her complain about it, even when she was repeatedly scrubbing out bedside buckets from me being sick. It meant a lot to me that she was so willing to take over and take care of me and our world. (Frank)
>
> There were days when he could hardly get out of bed without being sick, and it seemed silly to get upset over him not doing his dishes or not wiping counters. During dialysis, we just didn't have time for anything else. (Erica)

Treading the Fine Line: Balancing Fears with the Need to Protect

Several couples indicated a tendency to withdraw, or even to hide their fears from their spouses at times, out of fatigue or in an attempt to not only protect their spouse but to convince themselves that this was not "really happening."

> I think I withdrew a little bit, especially early on when there was no diagnosis. I think I went through a bit of a depression for the first 6 months after my creatinine started to rise, and I didn't know how scared to be, and I think I tried to shelter my husband from that a little bit. In a way, I just wanted to protect him. [after she was put on the transplant list] I felt like I once again had hope. At that point, I think I became fully open in my communication again. (Carol)
>
> I know there were times when my wife didn't tell me about health problems she was experiencing right away because she didn't want to frighten or worry me, but for the most part she did a great job of telling me what was going on. I also made sure she always knew she could depend on me to help her. I never wanted her to feel like her illness was a burden on me. (David)

Some had more difficulty expressing fears about their partner's illness:

> The last six months before the surgery, I was very worried and very scared. I was wanting to talk to anyone about it who I could communicate with who would listen to me talk or listen to me cry, and who could take in all of my worries and be very understanding. I think the closer the surgery got, although John and I could talk about anything else, he seemed a little more closed up, and I could tell he was just worried but didn't want to let me know he was worried. (Iris)
>
> I think maybe we were both trying to hide from the other person how scared we were. I was trying to be strong for her, and she was trying to be strong for me … [O]ver the course of [an] argument [we] started talking about what was really bothering us, and were able to open up about the fact that we were both scared notless … [After that argument] certainly we were less stressed, realizing that we didn't need to be stoic for each other. That was causing stress in that we each thought perhaps the other person was taking it too lightheartedly, and we realized, no, we're taking it pretty serious, and we have a strong faith, as far as church and stuff, and we spent a lot of time in prayer, trying to let go of it, and realized that there are some things that are beyond our control. (John)

Frank and Erica also noted a tendency to try to protect one another as they dealt with ESRD difficulties. His method for avoiding the issue was to use optimism:

> I think I annoyed her sometimes by always looking at the positives and trying to avoid getting scared, but I had to so I wouldn't focus on fear. I think I need a "light at the end of the tunnel" to focus on, whereas she was more open to talking about what she was scared of. (Frank)
>
> I think there were times that he didn't want to tell me when he was feeling bad and there were times I was terrified about his health that I didn't want to scare him so I kept it to myself … As we got closer to a transplant, we did talk more about what we were afraid of, but he was always trying so hard to be optimistic and hopeful so I still kept some of my fears to myself and talked to my family or friends instead. (Erica)

Different ways of coping with fear can lead to frustration or avoidance, but allowing for those differences within a relationship and recognizing that they exist, can even be healthy, and may be beneficial in helping communication grow and relationships succeed.

Sexual Concerns

While some couples noted an overall improvement in their sexual lives after the transplant experience was over and they were in full or nearly full recovery, most couples indicated some decrease in sexual desire or satisfaction throughout the illness and treatment.

Ann and Brian noted that their sexual relationship all but disappeared when she was ill:

> When I got sick, our sex life pretty much came to a screeching halt. I didn't have the energy, nor did I feel well enough to enjoy it. In addition, I was on medications that decreased sexual desire. (Ann)
>
> Sex life, what sex life? When she got sick, she didn't know the meaning of sex. Every once in a while we would try to make love, but she was just so sick that it rarely occurred. It put a strain on our relationship because I felt like she didn't care about me. Since the transplant, it has improved. (Brian)

On a different note, Iris described her feelings of being unattractive due to the catheter (placed for dialysis) which was hanging from her chest.

> I can recall that on dialysis, it was just a couple of days after I got out of the hospital, and my body was totally fine, but I had my catheter in and it was a little uncomfortable. But I told myself "you gotta prove to yourself that you're fine" and I remember wanting to make love to him one night. For the first couple of times I kept a shirt on because I thought it was very unattractive to have this thing coming out of me, because it was right here, right above my right breast. And of course men have this whole thing with breasts, and I was thinking, "man, this is so ugly." [B]ut...he never ever said anything about me being less attractive because I had this catheter … I've got this scar that's on my left side, from the tip of my finger up to here, it's a pretty good scar, but it fades a little as the months go on. I think he's just more, "it's okay, everything's going to be okay, your scars will fade in time and it's not that big of deal." I think it's more just me being a woman … So different female things go through my mind, is he grossed out because of my scar … I've asked him, and he's just always "it's no big deal, don't worry about it, you're you and I love you and it's not going to make that big of a difference"

Iris' husband reported that sometimes he had diminished sexual desire, but not for the reasons that Iris feared:

> Stress reduces [sex] drive. I think there were a few times where she came to me feeling like I was turning away from her, and it wasn't so much that I didn't love her anymore. It was just that, I was pretty shaken up about it. I'm a [helping professional], and I usually am rendering aid to other people and not needing it in return. It was real hard for me to deal with this whole macho ego thing. (John)

John's frank admission of his own fears may have helped alleviate some of Iris's concerns about her body's new scars and changes being the root of their problems; when asked what helped him work through this tendency to avoid Iris when he was feeling pulled in too many directions emotionally, he responded:

> Crying like a baby usually helps, [laughing] it does … (but) we started talking more and more and realized what the real issue was: that we were both so scared.

Frank and Erica noted that they, too, had some miscommunication and hurt feelings arise in the area of their sexual relationship.

> When he first got sick, it was hard for me because he didn't desire sex as often and I was insecure and felt that he didn't desire me. We got that talked through pretty quickly, and even thought I sometimes still had my feelings hurt if I offered and he declined, I knew it wasn't a personal rejection and that helped. (Erica)
>
> I think there were times when I was sick that I hurt my wife's feelings because I just didn't want to have sex. I was too tired or I felt bad, and I just couldn't be sexual. We talked about it a lot, and she understood in her head why this was the case, but she had a hard time not feeling rejected. I think in the long run it all turned out okay, though. I just spent time telling her how much I love her and find her attractive, and blamed the rest on my old, tired, sick body. We laughed a lot about it. After the transplant, things got better. (Frank)

However, Erica was able to empathize with Frank's exhaustion and lack of desire: "Dialysis drained him a lot, both from the physical experience of it and the time we had to commit to the treatments, so we were sexual much less often during that year."

Several couples indicated concerns about returning to an active sex life after the transplant:

> During dialysis, I'm sure the number of interactions was probably decreased … You're concerned about damaging this freshly attached organ, so there was some trepidation when we first started back into our relationship, to make sure that there was no pain or discomfort. (John)
>
> After his transplant, we were both a little scared about the process of being intimate again, but once we tried and realized he wouldn't "break" we were okay. (Erica)
>
> The stent terrified me at first. I was afraid my body would not work the right way since they had operated on regions that were pretty close to sexual areas, but everything works great. (Frank)

Sometimes sexual desire doesn't return post-transplant. However, after the treatments ended, they found ways to compensate. Kathy said,

> (During treatment) it was a little weird for us to make love when he was hooked up to the dialysis machine during the night. We tried to avoid it … After the transplant, now that he is taking so much medication, we don't have sex as frequently. However, we cuddle and are affectionate, and I feel very close to him.

Louis said,

> Due to the heavy medication, there has been a lower level of sexual desire on my part.

DISCUSSION

Comparison to Literature Review

The patterns of negative impacts from ESRD, which became apparent in the present sample of participants, were quite similar to those noted by Smith and Soliday (2001) in their review of related literature. They noted a similar pattern of changes in division of labor as one spouse became increasingly more ill. They quoted patients indicating feeling "useless" or feeling as though they were not taking adequate care of their responsibilities. This theme was echoed in the present research, through the aforementioned statements of Iris, Frank and Carol. In addition, Smith and Soliday noted that some of the most notable results of chronic kidney disease are financial problems and a feeling of exhaustion or low energy. As we have seen, the participants in the present research have described the manner in which the loss of jobs, energy and desire impacted them throughout this experience.

As for the loss of sexual desire and the communication issues that followed, Boss and Couden (2002) indicated that this pattern is not atypical within the chronic illness community. They suggested that "a husband with diabetes may shun his wife because the illness had impaired his sexuality, and she is confused by his emotional withdrawal and because he no longer touches her" (pp. 1353, 1354). Erica certainly experienced this with Frank. Additionally, Frank's withdrawal from sexual interaction may have been due not only to physical limitations, but due to feeling impaired sexually and not knowing how to adapt to the impairment. By communicating about their confusion and concerns, the potential for serious misunderstanding or permanent damage to their relationship was averted. The fears that Iris expressed as she described the changes to her own body might also be reflected in the research of Boss and Couden (2002), since her impaired sense of self-worth and value as a sexual being was impacting her ability to trust that John still loved her, and still found her attractive.

Communication was thus key to many of the couples in surviving this difficult experience. As Treif et al. (2003) noted,

> a high potential for conflict exists, as partners may cross the line from reminding to nagging, or struggle with how to respect their spouse's need for independence while dealing with their own fears about the consequences of poor disease management (p. 65).

Spouses of ill partners might want to help in any way they can, but they cannot make the final choice of how to cope with the illness itself, because that illness resides within the patient. Some of the participants in the current study reported protective behaviors toward their partners as well, often narrowly avoiding being over-controlling or "nagging." Some patients indicated feeling taken care of in this regard, whereas others felt less than grateful for the interference.

In the process of caring for their ill spouses in the best way they knew how, several of the participants in this study noted that they were not always positive about their tasks. Brian and David both expressed frustration at their wives for not being able to complete tasks or function normally, but also expressed some sense of regret for having felt that way. As Skerrett (2003) noted, "blame, both self and other, is usually a central feature of troubled couples and tends to be more toxic in couples with illness because there is a greater tendency for the blame to go underground. As one couple put it, 'How in the world could I ever admit that at times I blame her for getting sick in the first place and also blame her for not taking care of herself?'" It seems disloyal to be angry at someone who is struggling with a medical impairment, so the well spouse might be tempted to send that blame "underground." However, once buried, it can lead to resentment and further breakdown of the relationship.

Negative emotions such as anger or guilt are not the only topics that might be tempting for well spouses or patients to avoid. Rolland (1994) noted that healthy partners might refrain from expressing their concerns and fears out of a desire to avoid frightening or upsetting their spouse as she or he copes with the illness firsthand. However, they all indicated that when they opened up the lines of communication and shared openly with one another, they felt closer and more connected with their spouses.

Opening the lines of communication was not always easy for the participants in this study, and Iris and John described a "blowup" fight in which they finally realized they could not communicate in the stoic, closed-off fashion they had been using. As Skerrett (2003) reported, “it is a formidable challenge to support couple strengths amid unbearable pain, uncertainty, fear and loss. … [O]ne of the compounding dilemmas is the isolation that often develops between them” (p. 69). That isolation can lead to losing the sense of themselves as a couple, and instead becomes a lonely struggle.

Other sources of support were found to be very helpful for the participants in the present study. Many of the couples noted that they were more socially involved and immersed in the outside world following the transplant. This pattern is supported by other recent literature, such as Henderson (1997), who found that after recovering from cancer, patients

> thought about other people more, they preferred socializing with others more, and although they sometimes found it difficult to reconnect into a broader social network, they felt better when they were able to interact with people (p. 190).

Couples who are young and newly married might not find a social network of other young, newly married couples who can truly comprehend what they are going through. These feelings are echoed in the research of Smith and Soliday (2001). They reported participants saying, “our family is intact but (we are) much ‘older’ than our years” (p.175), as well as a woman who indicated that she felt “family and friends tend to stay away out of fear and pity” (p. 175).

Couples facing illness together may find that placing the emphasis on their needs as a couple and on supporting one another actually strengthens their relationships and is supported by other recent research. In a comprehensive review of the literature on couples facing chronic illness, Kowal et al. (2003) noted that “the onset and course of chronic illness does not necessarily have a detrimental influence on couples” (p. 301). Togetherness and teamwork may be what “normal couples,” or those not faced by illness, develop through years of shared life experiences. Perhaps the couples interviewed in the present study obtained a “crash course” in working as a team and caring for one another as a couple, rather than focusing on the “I” or “individual” needs first and foremost.

Limitations of this Study

Given the limited participant pool from which this study drew, it was difficult to find an adequate sampling of participants, and in today’s fast-paced society, meeting with couples from across the country in person was not practical or feasible for most participants. Thus, some richness of data is lacking. A second limitation of this research was the self-selection of participants. Five out of 6 of the participant couples were from a somewhat skewed population who chose to respond to a solicitation on the NKF Web site. Another limitation of this study was the retrospective nature of the data collection. Participants were asked to recollect their experiences from their current viewpoint, rather than being interviewed as they progressed through the ESRD experience. The heterosexual bias of the sample used for this study also presents a limitation. Additional couples, whether heterosexual or homosexual, might not be legally married but are involved in committed, long-term relationships, which could present a more diversified picture. The inclusion of couples who have divorced or separated after their ESRD experiences might provide insight as to the more detrimental aspects of new relationships being tested in such a manner.

Recommendations for Future Research

Researchers could devise a method for approaching all couples within a particular setting and offering them the opportunity to participate in a research study. To obtain an adequate sample size, this approach might need to be instituted across several settings, perhaps at large transplant facilities in several regions to alleviate location-related biases as well. Interviewing couples as one partner is initially diagnosed with ESRD, and then following them through illness, treatment and recovery would provide a more accurate representation of the lived experience of this process. This would entail a much greater time commitment from participants, which might limit participation, and would also require a more longitudinal design that could have impacts on research budgets and researcher availability. A sample population that was missed in this research includes those couples whose marriage does not survive and thrive through the experience of ESRD diagnosis, treatment and recovery. Throughout my research I was told of several couples who “stayed together” through the spouse’s transplant, then divorced soon thereafter. The experiences they might be able to offer would richen the data immeasurably, and one way of obtaining data from these couples would be by implementing the *in vivo*, longitudinal method as described earlier. Another suggestion might be to simply ask for experiences from all persons who have experienced this process of illness and recovery, individually or as a member of a couple to avoid the elimination of possible participants who are no longer members of a couple. Actual, in-person interviews would provide much richer data than the present study. In addition, future researchers might consider adding a quantitative portion to the interview process to verify results and avoid researcher bias. Future researchers might consider an established scale for marital satisfaction, or for current levels of stress within the relationship, to be completed at several points throughout the illness and recovery process by both partners.

Recommendations for Clinical Practice

As Skerrett (2003) noted, "the essence of the therapeutic work lies in shifting a couple's focus away from 'you' and 'I' to the 'we'" (p. 71). Therapists, physicians and other professionals who can help couples recognize the power within their relationship, as well as encourage them to see one another as more than a collection of symptoms or responsibilities, are crucial to maintaining healthy relationships throughout the illness experience. Rolland (1994) also argues that by working from a collaborative or "we" stance, partners can remember that they are not defined by illness and that their relationship has more substance than the physical conditions impacting it at the present time.

Many of the couples noted that they felt overwhelmed, frightened and unable to keep up with the daily tasks of living during the course of treatment. A couple who is feeling overwhelmed by simply surviving in the face of illness and the related chaos is unlikely to be a couple who can commit to spending many hours per week in counseling. Leading researchers and clinicians often suggest that couples engage in activities or assignments together outside of the session itself (Dattilio, 2002; Donovan, 1999; Weeks & Treat, 2001). As Skerrett (2003) noted, "in the chaos triggered by illness, regular time together, i.e. setting aside a weekly date night for fun, was typically the first thing to go, if it was ever pursued in the first place" (p. 76). Couples who are coping with the demanding schedule of doctors' appointments, dialysis treatments, hospital visits and daily experiences with physical exhaustion and decline may not be able to complete a rigorous clinical exercise, or even a simple therapeutic exercise. A more realistic approach might be asking couples just to listen to one another more. Their weekly "assignment" might simply provide a change of focus: trying to understand and communicate as openly with their partner as they are able.

Research suggests that by knowing what others have encountered as they traveled along similar paths, some of the sense of isolation and difference might be alleviated and anxieties lessened as their lives begin to change. For example, Boss and Couden (2002) note that

> the most stressful losses are those that are ambiguous. When people are unable to obtain clarity about the status of a family member, they are often immobilized; decisions are put on hold; roles remain unclear; relationship boundaries are confusing … (p. 1352)

Local social support for both the patient and the well spouse could be offered in many ways. For example, social workers are specially trained to help clients search within their community to find the resources available to them: financial aid, assistance with meals, child care or other practical aspects of life. Physicians and nurses can help patients and their partners anticipate reality by preparing them for the physical impacts of the disease and its treatments, from the effects of medications to dialysis to transplant. Psychologists, counselors and social workers can help couples find support groups, where they can meet others in similar situations. They can also help to prepare clients for the possibility of sexual difficulties or impediments. These methods could help mitigate the sense of being isolated from the community, and might help strengthen the web of trust and flow of information between patients, spouses and the treatment community.

FINAL COMMENT

The couples who participated in this study provide a detailed glimpse of the experience of living through ESRD and kidney transplant and a clearer picture of how this disease impacts young couples, which, in turn, can help those working in medical and mental health fields who might wish to help other couples in their practices who are coping with this illness. As a researcher, I greatly appreciated their courage and candor in discussing difficult topics, and believe the risks they took in sharing will have a positive impact on the lives of those following in their footsteps and facing ESRD and renal transplant in future years.

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The Critical Renal Challenge: Finding Godot, Not Waiting for Him: Screening, Early Detection and Treatment of Precursors of Chronic Kidney Disease

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U.S. demographic, social and medical trends are converging and threaten to reach a crescendo in the incidence and prevalence of chronic kidney disease (CKD), particularly affecting those in the later years of life. Government and medical resources are ill prepared to deal with the implications of this phenomenon and demographic population changes. It is imperative that existing programs be expanded and new approaches be developed to intervene earlier in the disease processes that precede CKD. Early childhood education, early screening and treatment of chronic conditions and more effective interventions in minority communities are critically needed. Waiting for kidneys to fail is not an option; there is no choice but to intervene sooner and better than ever before.

INTRODUCTION

A literary reference to Samuel Beckett's *Waiting for Godot* (1954) is particularly appropriate to our global kidney community. In many arenas, and in the not so distant past, professionals, patients and families were frozen in a seemingly passive role as renal disease progressed to the point that kidneys failed and either dialysis or transplant was needed.

Over time, however, state programs, voluntary agencies and treatment facilities have made significant strides in pre-dialysis education, care and planning. These have included the development of a wide range of printed and video educational materials and stage 5 chronic kidney disease (CKD) educational meetings for patients and family members. Programs such as the First Things First seminar at the Washington University Renal Clinic address the education and care needs of early-stage kidney patients, some of whom will never reach stage 5. However, despite increasing efforts to provide optimal care and planning, including early access placement for pre-dialysis patients, findings from the Dialysis Outcome and Practice Patterns Study demonstrate that only 54% of patients have a permanent access in place to initiate dialysis (Pisoni et al., 2002). It is clear that new perspectives and new initiatives are needed in the full continuum of care, from identifying individuals at risk for renal disease to comprehensive and timely planning for patients approaching kidney failure. Indeed, it is the position of this paper that the clinical approach must be significantly more proactive in the process of earlier detection, education and intervention into the diseases that lead to CKD. Godot must be found!

Community screening programs for many conditions (e.g., hypertension, sickle cell disease and diabetes) have been in place for decades. The goal of these programs was the early identification of various conditions so that individuals might pursue care and treatment. Programs have been conducted in such arenas as workplaces, schools, churches and community health fairs. In early programs, links to care providers and follow-up to determine if these health problems were being effectively treated were often missing. Consequently, medical conditions requiring control and treatment—and the possibility of preventing medical complications—were not comprehensively addressed.

A Kidney Disease Outcomes Quality Initiative practice guideline recommends that individuals found at increased risk for CKD should be further evaluated and those who have CKD should be treated (National Kidney Foundation [NKF], 2002). Following screening with intervention as necessary implies that patients will need to be educated about their treatment and care.

LITERATURE AND DATA REVIEW

Data trends demonstrate a significant increase over time in the incidence of reported End Stage Renal Disease (ESRD) cases (U.S. Renal Data System [USRDS], 2006). Between 1993 and 2003, the yearly incidence increased from a total of 64,492 patients in 1993 to 87,121 patients in 1998, and to 102,567 patients in 2003 (USRDS, 2006).

Particularly striking is the increase in incidence of ESRD patients over the age of 75: there were 11,335 in 1993, 19,432 in 1998 and that population cohort increased to 26,292 by 2003 (USRDS, 2006). This increasing incidence reflects the changing demographics of the United States as a whole. Average life expectancy is increasing dramatically and in some states, the age cohort of 85 years and over is one of the largest growing cohorts in the population pyramid.

The U.S. Census Bureau projects that between 2000 and 2050, not only will the population grow, but also the population will age. Looking only at the 65 to 84 U.S. age cohort alone, the growth is in the magnitude of 30,794,000 (2000) to 65,844,000 (2050). Perhaps most striking is the growth of the 85+ cohort, which increases from 4,267,000 (2000) to 20,861,000 (2050); (U.S. Census Bureau, 2004). Because we recognize the age-loading characteristic of CKD, the implications are clear: kidney failure in the overall population will continue to increase and possibly accelerate.

Continuing the analysis by the use of percentages instead of actual numbers more clearly illustrates the phenomenon. A striking comparison between 2000 and 2050 is the proportion of the population over the age of 65: 12.4% in 2000 versus 20.7% in 2050. One-fifth of the U.S. total population will be over age 65 by 2050 (U.S. Census Bureau, 2004). USRDS and U.S. census data agree that as America's population grows and ages, it will be in lockstep with the increase in the societal burden of ESRD.

To scientifically examine reasons for these increases, we must address the precursor co-morbidities that result in eventual kidney failure, and the population groups that are disparately affected by these processes. Diabetes and hypertension continue to be predominant etiologies for the development of stage 5 CKD, accounting for 73,649 patients in 2003, or approximately 72% of the total incidence; diabetes alone accounted for 43% of the incident cases in that year (USRDS, 2006).

USRDS data demonstrate that the incidence of reported ESRD is particularly high in the African American population. In 2003, 29% of the total 102,567 incident cases were African American. Because the African American population accounts for approximately 11 to 12% of the total population, this disproportionate burden (a factor of 2.4) of serious chronic illness is dramatic. Also remarkable is that 13% of the incident cases in 2003 are Hispanic. Although anecdotal reports over the past year or so indicate that incidence rates in general have leveled out somewhat, we are left with the reality that more patients present themselves for ESRD and CKD care every year (USRDS, 2006).

More males than females experience ESRD, and the 2003 data show a 54 to 46% male–female split. One bright statistic demographically is that the age cohort 0 to 19 years of age shows only a 22% increase from 1993 to 2003, numbering 1,093 cases in 1993 to 1,337 in 2003. This compares to the 232% increase in the 75+ age cohort over the same time frame (USRDS, 2006).

Evidence of the burden of these diseases is clear. In Missouri, for example, emergency room (ER) visits for hypertension and diabetes, comparing Caucasians to African Americans, are illustrative. For essential hypertension, Caucasians made 1.1 ER visits per 1,000 population compared to 4.5 ER visits per 1,000 population for African Americans. A similar discrepancy occurs for patients who have diabetes with complications: 0.7 visits per 1,000 population for Caucasians and 2.9 visits per 1,000 population for African Americans (Reed, 2004). Granted, a portion of this racial ER visit disparity may be due to the different incidence of these chronic illnesses in the minority populations, but contributing factors may also be found in differential access to primary health care and differential economic capabilities to buy healthful food and needed medications.

Illustrating the epidemiology of ESRD among African Americans, Martins et al. (2002, p. 1) noted that

> although disparities and outcomes among African Americans compared to whites with respect to cardiovascular disease, cancer, diabetes, infant mortality, and other health standards have been well described, these disparities are most dramatic with respect with kidney diseases.

ESRD for African Americans occurs at approximately four times the rate of Caucasians (National Kidney Disease Education Program, 2005). Health practitioners may find it harder to achieve blood pressure control in African American patients and different combinations of medications may be required. Interplay of many factors, including environmental, genetic and economic, contributes to the racial incidence differences in both CKD and ESRD, and a complete understanding is not known at this time. Not only do African Americans have a higher incidence of diabetes than Caucasians, diabetes and hypertension together in the same patient take a higher toll on renal functioning than just one disease by itself. Wright et al. pointed out that "African Americans are six times more likely to develop ESRD from hypertension than whites" (2002, p. 2421).

States vary in terms of their epidemiologic surveillance of chronic conditions. In Missouri, health disparities are followed not only by state offices but by projects funded by the Missouri Foundation for Health. In Missouri from 1998 to 2002, death rates from diabetes were 23.2% per 100,000 for Caucasians (as reflected on death certificates) compared to 35.1% per 100,000 in the Hispanic population, while the death rate for African Americans was 49.9% per 100,000 (Reed, 2004).

For now, we need to focus on what can be done with tools at hand. We must focus on better use of pharmacological agents and better control of blood sugar levels and strive to provide better and more consistent primary health care access.

Crossing clinical lines on an important issue, a small study (103 subjects) in the VA Health System reported that African Americans rated their physicians as less communicative and consequently less trustworthy (Gordon et al., 2006).

Finally, an important factor in this phenomenon of diabetes, hypertension and CKD is the epidemic of obesity. Jeffrey Koplan, former Director of the Centers for Disease Control and Prevention (CDC), stated that "obesity is as dramatic as anything I've seen in public health. It is the health problem of the 21st century" (NKF of Kansas and Western Missouri, 2006). Efforts to reduce obesity should include both adults and children.

Consider obesity rankings for the state of Missouri as an example. Missouri does not rank well. The national average for overweight children ages 10 to 17 is 15%, and while Missouri's rank of 16% is only 1% higher, only 9 states have more than 16% obese children (Henry J. Kaiser Family Foundation, 2003). Missouri's adults fare no better; Missourians 18 and over have an obesity rate of 24.9%, which is slightly higher than the U.S. rate of 23.2% (Hitti, 2005). Stated another way, one-fourth of adult Missourians are obese.

The CDC defines childhood obesity as the term used to refer to children and youth between the ages of 2 and 18 years who have body mass indexes (BMIs) equal to or greater than the 95th percentile of the age- and gender-specific BMI chart (Missouri Department of Health and Senior Services, 2005). Nationwide, more than 9 million children over 6 years of age are classified as obese while many millions more are overweight and at risk for becoming obese if they or their parents do not aggressively change their lifestyles (NKF of Kansas and Western Missouri, 2006). In a population-based study, approximately 60% of obese children 5 to 10 years old had at least one cardiovascular disease risk factor (e.g., elevated total cholesterol, triglycerides, insulin or blood pressure), while 25% had two or more risk factors (NKF of Kansas and Western Missouri, 2006).

Unless the current epidemic of obesity in the United States is dramatically altered, a resulting epidemic of kidney disease must be anticipated. Therefore, preventing obesity can be expected to reduce, among other conditions, the potential of kidney disease. Obesity, diabetes, high blood pressure and the early onset of these factors in childhood further stress the need for early interventive approaches, rather than passively "waiting for Godot."

In summary, this review clearly indicates that the incidence of ESRD is increasing dramatically over time, the U.S. population is aging markedly and the looming entry of the baby boomer cohort on the health care system will be significant. In addition, CKD and its precursor diseases, diabetes and hypertension, are significantly more frequent in African Americans and Hispanics than Caucasians. For example, in Missouri, death rates from diabetes alone are double in African Americans than Caucasians, with Hispanics in between; there are multifactorial aspects to the disparate rate of incidence in minority populations and the confounding influence of obesity makes the problem worse. Finally, as in our earlier example of African Americans' and physicians' communication, there are indications that the health care system does not serve minority populations as well or as efficiently as it does the Caucasian population. Given these data and demographic characteristics, we are faced with daunting challenges for the future, as more citizens live longer lives with increasing numbers of related chronic medical conditions. The remainder of this article explores different approaches in addressing these trends, current interventional programs and suggestions for further interventions.

BACKGROUND ON INTERVENTION APPROACHES

In recent years, various programs for patients at risk for CKD have been developed. These programs, often funded by state and volunteer agencies, have attempted to not only screen individuals but also follow up with them to encourage and facilitate medical intervention. One of the early programs in the 1980s, entitled "Community Screening and Intervention for Type II Diabetics at Risk for Renal Disease," was funded by the Missouri Kidney Program. The goal of this program was to link community health clinic diabetic patients, as identified with microalbuminuria, with renal specialists at a major university medical center.

More recently, the NKF developed the Kidney Early Evaluation Program (KEEP) Program (2005), a national community-based program to identify patients with risk factors for CKD. The Missouri Kidney Program has also funded a screening and follow-up program. Both of these ongoing programs are described in the following paragraphs.

Identifying individuals at risk for CKD and referring them to care providers is an extremely important issue. Controlling conditions such as hypertension and diabetes early in their course holds the promise of preventing or delaying complications, including CKD. Identifying patients with early CKD and securing specialty care with nephrologists, in turn, allows for intervention and, if needed, timely planning for later stages of CKD and dialytic and/or kidney transplant planning.

Waterman and Whitlock (2003) collaborated with the Missouri Kidney Program to analyze data obtained from a major study funded by a CDC Reach 2010 grant. This grant afforded a statewide analysis of members of select minority and majority communities within the state to analyze knowledge and attitudes regarding diabetes and organ donation.

Research modalities included telephone surveys and in-person focus interviews in target communities around the state. It was felt that the degree and quality of input from the participants was quite high. One overall conclusion was that Caucasians, African Americans and Hispanics differ in their knowledge and attitudes about diabetes and organ donation. There is no doubt that sensitivity to the differences and needs of these communities is essential to increase knowledge, improve attitudes and promote healthy behaviors. Tailored health education directed at correcting misinformation must be accessible to minority communities and must be expressed in culturally competent ways. The study concluded that future research should focus on learning more about the socioeconomic differences within and between racial communities that affect the groups' perception of diabetes and kidney disease. In addition, significant education must be targeted to young people, as they have a better chance of learning positive habits early, whereas older people have more difficulty changing unhealthy diets and lifestyle habits.

Partial findings concluded that, compared with Caucasians, African Americans and Hispanics agreed that they needed more education about diabetes in their home communities. They tended to have less understanding of the relationships between smoking, exercise and diabetes, or that dialysis and kidney failure could be complications of diabetes. There was also less understanding that complications of diabetes could be preventable.

Patients’ willingness to donate organs across racial groups was high. Eighty-nine percent of respondents reported they would consider donating one of their kidneys to a family member. However, African Americans were less likely to donate their organs when they died or through living donation as compared to Caucasians (Waterman & Whitlock, 2003).

The national KEEP project, mentioned earlier, is sponsored by the NKF. Entry criteria for inclusion in the project included a known history of diabetes or hypertension, or a family history of diabetes, hypertension or kidney disease. KEEP’s initial program, surveying 900 individuals in 21 cities, showed that CKD was more common than anticipated (NKF, 2005). By 2005, 37,155 individuals had met the criteria and were included in the report.

Significant results included that 52% of participants reported hypertension, 16% reported cardiovascular disease and 25% (versus 6.4% in the general population) reported diabetes. This extensive report noted that obesity is a common problem in those screened (NKF, 2005).

Another example of a screening program is the Early Intervention Program, in operation since 2001 (NKF, 2005). Conceptualized and run by the NKF of Kansas and Western Missouri, and partially funded by the Missouri Kidney Program, the Early Intervention Project has screened more than 9,700 total subjects. Data have been collected on these subjects and analysis is currently in progress.

Methodologically, outreach efforts are made through health, community, church and workplace groups in Western Missouri, Kansas City, and to a lesser extent, Southwest Missouri. A team works with persons who desire screening to measure blood pressure, microalbuminuria and glucose levels and results are reported on-site to the participants.

Preliminary analysis of the data indicates that, consistently, 51 to 53% of the 9,700+ patients screened possess one or more high-risk factors for developing kidney disease. This rate is similar to some of the KEEP results and reinforces the incidence and prevalence of these chronic health problems in the general population and particularly in minority communities. To the extent that these risk factors are generally detected in persons who were unaware of their health status prior to the screening should be of special concern to professionals in the renal community. An integral part of this program is a referral and follow-up process that encourages patients to follow up with health care providers and then monitor by telephone their actual performance in receiving the recommended health care.

In this ongoing project, increased efforts will be concentrated on extended program expansion into Southwest Missouri, especially in light of the growing concentrations of Hispanics and African Americans in that area.

Another important intervention program has begun in the Kansas City area, conceived and sponsored by the NKF of Kansas and Western Missouri (2006). Echoing the findings from the Reach 2010 project (CDC, 2007), the focus in the Kansas City program is on the issue of childhood obesity via a program called KID POWER.

The program was developed through collaboration among local public and private medical, social and educational institutions. Because of the connections among kidney disease, high blood pressure and diabetes, the program uses a two-pronged educational and motivational approach to decrease childhood obesity. In addition to continuing medical educational courses for primary care providers on the assessment and treatment of childhood obesity, the KID POWER program focuses on healthy nutrition and activity challenges for children 8 to 13, popularly referred to as "tweens."

KID POWER is a motivational program that educates tweens on the benefits of healthy lifestyles. The overall goal of KID POWER is to develop and maintain healthy nutrition and activity habits in tweens with the ultimate aim of reducing the incidence of the 2 major causes of preventable kidney disease, high blood pressure and type 2 diabetes.

KID POWER consists of 3 main components:

1. A calendar
2. The curriculum
3. Training and coordination of site directors.

This approach is also designed to ensure that parents or guardians of the young participants understand and continue to reinforce the basics of the program, via an adult module that is provided as a part of the "graduation ceremony" at the end of each session. The nutrition course was designed by a registered dietitian who specializes in working with children. KID POWER combines culturally-sensitive nutritional education, physical activities, cooking classes and incentives that increase potential for nutritional and lifestyle modification. Recipes, snack and meal preparation ideas incorporate lower-calorie versions of culturally-appropriate foods that the children's families are accustomed to eating. By spring 2006, 19 sites were serving 918 tweens participating in KID POWER. Of the participants, 56% were male and 44% female. The average age was 10.9 years. All but 2 of the 19 sites hosted parties with healthy snack demonstrations. The curriculum materials include colorful newspaper-type publications and much effort is made to disseminate these in area public school settings to try and focus increased attention on healthy behaviors (NKF of Kansas and Western Missouri, 2006).

In terms of program outcomes, tween participation in nutrition and physical activity behavior is measured by a self-report tool called Check Your Health. This 13-item questionnaire assesses behaviors directly addressed by the curriculum such as eating 5 fruits and vegetables per day, spending at least 1 hour a day in motion, eating breakfast and watching less television. Participants complete this questionnaire at the beginning and at the end of the 12-week program. The results indicated a statistically significant improvement in nutrition and physical activity.

Tween participants in selected sites underwent additional measures of nutrition and physical activity behavior at the beginning and end of the 12-week program. These measures included a 24-hour dietary recall, heart rate monitoring during moderate physical activity and the PACE + physical activity questionnaire as used by the KID POWER program. The results of the dietary recall were difficult to interpret due to many incomplete records, but indicated that sugar drinks should be a focus of increased education for subsequent KID POWER challenges. The results of the heart rate monitoring suggested improved physical fitness in KID POWER participants by the end of 12 weeks and the results of the PACE + indicated that participants were being physically active for an hour longer more days a week at the end of period than at the beginning.

Finally we will discuss a 6-state program, Care Improvement Plus, that is developing innovative team approaches to dealing with selective chronic diseases and conditions, which offers specialized care for Medicare beneficiaries (Care Improvement Plus, 2006). This new approach is designed to comprehensively cover individuals living with diabetes, heart failure and ESRD. Essentially, it combines traditional Medicare Parts A, B and D coverages, using a case management model. Traditionally, health plans and insurance companies have focused their efforts on helping members with health problems after they arise. These new specialized care plans take a more preventive approach and use disease management technologies and other services to attempt to prevent further health deterioration.

Research has shown that disease management can help improve health outcomes such as:

- A reduction in blood pressure can reduce heart attacks, strokes and deaths from cardiovascular disease.
- Improving blood sugar control of people with diabetes reduces their risk of developing complications such as eye, kidney and nerve disease.
- Regular eye exams and timely treatment can prevent diabetes-related blindness.
- Regular foot examinations and monitoring can prevent diabetes-related amputation (Care Improvement Plus, 2006).

Health care industry experts recognize the potential for these specialized care plans and other disease management-focused initiatives to address the looming

Medicare budget crisis. As documented earlier in this paper, with the aging of the American population, the first cohort of the baby boomers will become eligible for Medicare in 2011. It is predicted that their medical costs will completely overwhelm federal and state budgets (Care Improvement Plus, 2006). Medicare leaders hope that offering plans specifically geared toward meeting the needs of people with chronic health problems will lead to better health outcomes for those people and lower costs for the health care system overall.

Nonetheless, it is important to acknowledge that while this is positive for Medicare beneficiaries, these beneficiaries have Medicare coverage either because of severely impaired health status prior to 65 or the attainment of age 65. By that time, the ravages of chronic disease have begun or have taken their toll on the individual patient.

Therefore, our culture must develop the same kind of disease management and specialized care programs for younger populations. Echoing the sentiments in earlier sections of this article, we must follow the lead of innovative programs such as Care Improvement Plus and experiment with this team-based model in younger patients with chronic care conditions in those stages in their lives where we can still impact and prevent the serious health consequences of diabetes, hypertension and obesity.

In summary, innovative programs are being undertaken at national, state and local levels. KEEP and the Early Identification Programs are examples of efforts aimed primarily at adults with the primary focus of early detection and referral for treatment of high-risk factors. A salient point is that a significant number of those screened are found to have health conditions of which they were not aware. Hopefully, with early intervention combined with follow-up, progression of kidney disease or loss of kidney function can be positively affected.

In addition, agreeing with research findings, particularly in minority communities, it is apparent that interventions into the lives of young people can be effective. Other evidence-based ideas include finding ways to interface with Parents As Teachers and Head Start programs to see if diet, exercise and lifestyle education can be made part of these early educational programs.

IMPLICATIONS FOR FUTURE PLANNING

It is expected that findings from the Reach 2010 project discussed earlier will be further confirmed in the Kansas City Early Intervention Project. Research strongly supports the view that education focusing on how people with diabetes should care for themselves, especially stressing the importance of not smoking and getting regular exercise is needed, particularly in minority communities. Focus groups with minority populations in our state revealed that school-based interventions using culturally-sensitive education may offer the best opportunity to devise effective educational strategies. Education about the need for organs in the African American and Hispanic communities is necessary to promote transplantation. Providing additional information in a culturally-sensitive fashion to dispel myths about organ donation may also ease the anxiety people may feel about donating their organs. The need for continuing screening, referral and follow-up is obviously critical, particularly in communities where access to health care is limited. Disease management and team-based care delivery systems in younger populations to better manage patients with obesity, diabetes and hypertension may also help to prevent serious complications and CKD.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

Social workers and the rest of the treatment team have to come to a philosophic understanding that we have to turn our attention to the early detection and treatment of the diseases that underlie CKD. While there is general understanding that the incidence and prevalence of diabetes, hypertension and obesity is significant in the general population, it is even more pronounced in minority communities. Unfortunately, financial or insurance resources to provide early detection services are simply not available at this point in time, nor is the general medical community attuned or organized to deliver comprehensive care to these chronic conditions for patients in all life stages.

Some conclusions are obvious:

1. Education about health, diet and staying fit has to start early in life and become integrated into our early childhood educational system.
2. Screening, referral and education have to become more commonplace.
3. Cultural competency has to become more prevalent if we are to address the special health concerns of our growing minority communities.
4. We have to become involved in the health policy processes of our local, state and national governments to promote adequate funding for early detection and early treatment.

5. We have to become more evidence- and outcomes-based in our everyday professional lives so we can prove what we know from clinical practice.
6. We have to build intellectual bridges with all health professions to shift our collective thinking away from "waiting for kidneys to fail" to strategies for intervention and prevention, particularly with regard to diabetes, hypertension and obesity.
7. We have to become involved with organizations, such as the American Diabetes Association, that focus on precursor diseases.
8. We have to urge state and national policy makers to devise a social/health policy that aggressively uses techniques, such as disease management strategies, if we are to effectively tie care plans together, and use the strength of multidisciplinary teams to effectively serve patients with chronic conditions, particularly in the younger age cohorts.

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Assessing Readiness for Change: A Novel Application of the Transtheoretical Model of Health Behavior Changes in a Pre-Renal Insufficiency Clinic

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The transtheoretical model of health behavior change was applied by a social worker in a Canadian pre-renal insufficiency clinic as a method to facilitate and support the behavior change required by patients to initiate renal replacement therapy. A chart review of 102 patients was undertaken to determine the ratio of patients in various stages of change and determine the statistical relationship between stages of change, activities of daily living and demographic characteristics. Major findings revealed a significant correlation between stages of change and activities of daily living and stages of change and age. Future research should focus on developing a standardized staging tool for this population. Implications for social work practice are discussed.

INTRODUCTION

End Stage Renal Disease (ESRD) and renal replacement therapy (RRT) have immense psychosocial implications. According to the Canadian Association of Nephrology Social Workers (2005), the person with ESRD is faced with “role adjustment” and changes that can affect all aspects of their lives, ranging from emotional, vocational (work), financial, sexual and physical. Often people feel “numb” or in disbelief when diagnosed. The Renal Management Clinic at the Toronto General Hospital is multi-disciplinary clinic, located in a large urban multi-cultural Canadian city. Its mandate is to manage the initiation of RRT for people with ESRD (Giles, 2004). Each patient who is seen at the team clinic is assessed and followed by a renal social worker until they have made the decision to initiate 1 of the 5 RRT options, which include: no treatment, day or evening hemodialysis, peritoneal dialysis or kidney transplantation. The purpose of the assessment is to identify the patient’s treatment goals and provide counseling, support and education that will facilitate them in realizing their goals. This includes identifying and assisting in overcoming (where appropriate) any barriers to obtaining their goals.

To assist the patients and health care team with facilitating the patient behavior changes required to initiate treatment, a novel application of the transtheoretical model (TTM; Prochaska, 1995; Prochaska & DiClemente, 1982; 1983) and motivational interviewing (MI; Berg-Smith et al., 1999; Emmons & Rollnick, 2001) was applied to social work assessments.

Within this framework, an understanding of patient motivation and the ability to use MI are central to assisting the patient with achieving the behavior changes required for life-altering treatment decisions. This motivational style of assessment and interviewing is based on the stages of change model (Prochaska, 1995; Prochaska & DiClemente, 1982; 1983), which provides clinicians with “… conceptual framework for understanding the process of individual behavior change” (Berg-Smith et al., 1999, p. 399). By staging each patient, social workers and other members of health care team can plan and tailor MI interventions based on each stage, thereby respecting and supporting each patient’s personal and psychosocial processes.

Prochaska’s stages of change concept is widely used by clinicians and researchers in several other fields, such as addictions, diet and physical activity. However, a careful search of Medline, CINALH and psycINFO databases failed to reveal any research that has applied the stages of change conceptual framework to pre-RRT ESRD patients.

TTM OF CHANGE AND MI

The goal of utilizing the TTM in the context of the Renal Management Clinic (RMC) is to provide medical information and psychosocial interventions in a patient-centered context that will support patienst as they move toward making a decision to initiate RRT-based decisions. According to Christensen and Ehlers (2002), ESRD patients face an extreme loss of personal control as the diagnosis “… entails a variety of chronic, recurrent stressors, significant change in lifestyle, disruption of familial roles and social identity, and threatened personal control” (p. 717). Therefore, within the context of social work psychosocial assessment and intervention, the stages of change allow for recognition of the difficult and complicated psychological process of adjustment necessary to facilitate the behavior change required to initiate RRT. The TTM construct, although not applied in RRT, has received empirical support in other health-related behavior change studies on topics such as smoking cessation, exercise, dietary compliance (Prochaska et al., 2005) and medication adherence (Erickson & Muramatsu, 2004).

According to Prochaska et al. (2005), the TTM, or stages of change, integrates four theoretical constructs central to change (p. 137):

1. Stage of change: Intention to take action
2. Decisional balance: Pros and cons associated with behavior's consequences
3. Self-efficacy: Confidence to make and sustain changes in difficult situations
4. Processes of change: 10 cognitive, affective and behavioral activities that facilitate change

Prochaska (1995) argues that change unfolds over a series of six stages: precontemplation, contemplation, preparation, action, maintenance and termination (p. 408). However, in the context of the RMC only the first four stages are utilized to assess patients' motivation and emotional readiness for change: precontemplation, contemplation, preparation and action. According to Prochaska (1995),

> stages are fundamental to understanding change because the concept of stages provides a temporal dimension, and change is a phenomenon that unfolds over time … stages are dynamic … but unlike states they do not change so easily and thus require special efforts or interventions. (p. 409)

Pre-contemplation is the stage at which a person has no intention of changing behavior in the foreseeable future. Many individuals in this stage are "unaware or under aware of their problems" (Prochaska, 1995, p. 409). In a study of healthy eating in diabetes patients, Vallis et al. (2003) found that pre-contemplators were "the most heterogeneous group and that they may benefit most from individual interventions."

The next stage in the model is contemplation. In this stage, people are aware that a problem exists and are seriously thinking about overcoming it but have not yet made a commitment to take action (Prochaska, 1995, p. 409). According to Prochaska et al. (2005), "contemplators continue to overestimate the costs of changing and, therefore, are ambivalent and are not ready to take action" (p. 138). The next stage in the continuum is preparation. Preparation is a combination of intention and some attempt at behavior change, as well; individuals in this stage are intending to take action immediately (Prochaska, 1995, p. 410). The final stage that is relevant in the context of the RMC is action. Action is characterized by actual behavior changes; individuals modify their behavior, experiences and/or environment in order to overcome their problems (Prochaska, 1995, p. 410).

More recently, MI, which is based on the TTM, has been used with a variety of behaviors such as smoking, medication compliance, diabetes management and HIV/AIDS risk reduction (Emmons & Rollnick, 2001, p. 68). Originally developed by specialists in the addictions field, MI was designed to help therapists and counselors avoid making inappropriate assumptions regarding their clients behavior changes (Emmons & Rollnick, 2001, p. 69). MI provides practitioners an opportunity to explore the process of behavior change and approach assessments from a truly client-centered perspective. MI and TTM are, thus, patient-centered approaches because they help reduce the pressure to change experienced by the patient, and fears that are associated with that pressure. By reducing external pressure, a patient's fear may give way to the insight needed to move from one stage to the next.

MI and the stages of change model have been simplified and adapted for use with patients in brief clinical encounters, such as dietary adherence (Berg-Smith et al., 1999, p. 399). The results of using a simplified stages of change model in dietary adherence among adolescents, showed promising results in that 127 adolescents, who attended an initial in-person motivational intervention session and follow-up counseling sessions, had a statistically significant reduction in calorie and fat intake (Berg-Smith et al., 1999, p. 407). MI may be of assistance with the RRT population because many clinicians start with behavior change requests that are action-orientated and then wonder why the patient is "non-compliant." For example, they may tell a patient that they need to start RRT immediately, even though the patient does not feel ready. This, in turn, may lead to a breakdown in the therapeutic relationship because both clinician and patient do not feel understood by each other.

RESEARCH QUESTIONS

This study's central aim was to describe the ratio of patients in the various stages of change. The secondary aim was to see if there were any relations between the patients, assessed stages of change and other demographic and psychosocial variables. According to Christensen and Ehlers (2002) "a diagnosis of ESRD entails a variety of chronic, recurrent stressors, significant change in life-style, disruption of familial roles and social identity, and threatened personal control" (p. 717). Therefore, it was expected that theses psychosocial factors would weigh heavily on individual decisions to consider RRT. Consequently, it was hypothesized that those who were not independent with activities of daily living (ADLs) would be less likely to be in the preparation or action stages of change. Additional research questions centered on whether demographic variables such as age, gender or English as a first language would be associated with stages of change.

METHODS

Design

The methodology for this project involved using a retrospective cross-sectional statistical analysis of variables identified in the RMC social work assessment notes. This method is described as practice-based research (PBR), which Epstein (2001) defines as "the use of research-inspired principles, designs and information gathering techniques within existing forms of practice to answer questions that emerge from practice in ways that inform practice" (p. 17).

Data Collection

All of the data for this research was collected by a single renal social worker, which Epstein (2001) maintains will enhance the validity and reliability of the research as the workers are the most familiar with the cases (p. 29). The data were collected over a 3-year period, beginning in August 2002, in which 102 patients were assessed by the social worker. According to Epstein et al. (1997), the advantages of using retrospective practice data include the fact that "it is less intrusive to patients and staff … Daily patient care routines are less likely to be disrupted when data collection focuses on available record documentation" (as cited in Dobrof et al., 2001, p. 108).

All of the data were collected during initial social work assessments and recorded on a standardized RMC Social Work Initial Assessment form that was adapted to include TTM stage of change assessment. The form records information such as demographic data, pertinent psychosocial data (including employment history), housing situation and education levels. Additionally, the form collects data regarding medical information, including past medical history, level of independence with ADLs and other co-morbid medical or functional conditions. ADL data were collected at initial assessment by noting what ADLs, if any, patients needed help with. If help was needed with one or more ADLs, patients were considered ADL-dependent. Examples of ADLs included in the assessments are dressing, getting out bed, meal preparation, transportation, bathing, shopping and errands.

The criteria for assessing stage of change at the RMC was based on social worker assessment of the patients' responses to discussions about their treatment options. These discussions then formed the basis for their designation on the stage of change continuum. Criteria for stage assessment are based on what patients say about being ready for RRT. Examples are included on Table 1.

Table 1

Examples of Criteria for Stage of Change Designation

PRE-CONTEMPLATIVE Patients are not contemplating treatment	CONTEMPLATIVE Patients are contemplating treatment	PREPARATION Patients are taking steps to prepare for treatment	ACTION Patients have taken action toward treatment
"I don't want dialysis."	"Not sure if I want any treatment."	"I will most likely choose X when the time comes."	"I am not pursuing any treatment."
"No need for dialysis yet."	"I'm looking into options, but have not made up my mind."	"I have an appointment for AV access or PD catheter."	"I have a PD catheter."
"I feel fine."	"I want a second opinion."	"I have an upcoming test for a transplant."	"I will start hemo next month once my access heals."
"Will wait until it gets closer."	"I am considering PD, HD, transplant, etc."		"I have AV access."
			"The transplant work-up in progress."

Data Analysis

Data analysis was conducted by utilizing non-parametric statistical tests, in particular cross-tabulation and the chi square test of association. The association between demographic variables, stage of change designation and psychosocial risk and priority status were all tested. Moreover, frequencies were tabulated for all of the pertinent variables collected on the RMC social work assessment. The single parametric test consisted of a one-way analysis of variance (ANOVA), followed by a bonferroni post-hoc, which looked at age of patients and stage of change. All of the above-mentioned statistical analyses were performed using the statistical software package (SPSS).

Results

ADLs

When the pre-contemplative and contemplative categories were collapsed with this sample of renal patients, it was found that patients who were not independent with ADLs were associated with being pre-contemplative/contemplative about RRT. The association was significant ($p = 0.03$).

Demographics

The analysis included a sample size of 102 renal management patients; the mean patient age was 64.74 years (ranging from 27 to 90 years). Of the patients, 60.8% were men, 39.2% were female, proving a good distribution with gender. Of the sample, 42% were born outside Canada, 24.5% were born in Canada and 34% were of unknown origin. However, 81.4% of the sample was English-speaking.

Stage of Change by Demographics

One-way ANOVA was used to examine stage of change by age of patients. Significant differences were obtained ($p = 0.012$) and this was followed by a Bonferroni post-hoc test that indicated that there was a significant difference in age between those in the pre-contemplative stage and those in the action stage. Analyses revealed that the mean age of those in the pre-contemplation stage was 70.1 years while those patients in the action stage had a mean age of 51.89 years. Interestingly, the mean age of patients was highest in the pre-contemplative stage, with the mean age dropping for each stage of change after pre-contemplation (contemplation, 63.4; preparation, 62.1; action, 51.89). No association was found between stage of change and gender, language and place of birth.

Stage of Change

Regarding the stages of change, 33.3% of the sample were in the pre-contemplative stage, 45.1% were in the contemplative stage, 10.8% were in the preparation stage and 8.8% were in the action stage. These frequencies show that a far greater percentage (78.4%) of those assessed at the RMC are in the pre-contemplative/contemplative stages with regard to considering RRT, producing implications for social work interventions.

IMPLICATIONS FOR PRACTICE

This analysis is the first to examine the stages of change model with a population of pre-RRT ESRD patients. Not being independent with ADLs was associated with being in the pre-contemplative and contemplative stages of change. This suggests that those patients may already have significant psychosocial and functional challenges, to which a diagnosis of ESRD and consequent RRT discussions may be overwhelming.

In the context of assessing those ESRD patients who require assistance with ADLs, it may be clinically advantageous to be cognizant of the multiple stressors and challenges this population faces and the subsequent trend for them to be pre-contemplative or contemplative regarding RRT. This is particularly worrisome given that options for RRT for this group may be limited due to the nature of their abilities. Receiving home dialysis may not be an option for this group if assistance is not readily available. This limits the treatment options that may allow the patient to be more empowered over their treatment, namely "… home patients have the opportunity to be much more actively involved in treatment delivery and direction" (Christensen & Ehlers, 2002, p. 712).

Thus, to remain more autonomous, those who require ADL assistance and extra supports may at most end up ineligible for the more empowering home-based RRTs unless the right level of ADL supports are initiated. Thus, to provide a fair choice of RRT options to all patients, assistance with ADL support will be crucial for those who require home-based RRT. Otherwise, only those who are already autonomous will receive empowering home-based RRTs.

In this sample of renal management patients, a significant difference in age was found between patients who were pre-contemplative and those who were in the action stage. Not surprisingly, those in the pre-contemplative stage were significantly older than those in the action stage. This may be attributed to the value of health throughout the life span. Busschbach et al. (1993) found that the young and elderly respondents in their research examining the utility of health at various stages in life of ESRD patients believed health in the early periods of life to be twice as important as in the last decade of life (p. 153).

The TTM posits that there is a time-orientated progressive process that is involved with change, which therefore suggests that people will progress through the changes. However, this study revealed that those in the pre-contemplative stages had a mean age of 70.71 years. Perhaps, age precludes one from aspiring to make the necessary cognitive adjustments required to commit oneself to a life-long course of dialysis treatments.

Hansberry et al. (2005) found that many elderly individuals have an improvement in their quality of life and social support once their kidney disease is identified and treated. Therefore, social workers that work with elderly ESRD patients who are pre-contemplative or contemplative about accessing RRT must be aware that these patients may benefit from stage-based interventions specifically targeted to address their ambivalence and contemplation.

Christensen et al. (1991) found that belief that one's health was controllable was associated with less depression in ESRD patients "[underscoring] the adaptive value of congruence between control beliefs and objective circumstances in chronic illness" (p. 419). It is possible that education and support, which empowers patients to regain some control over their illness, may be beneficial. It would be interesting to examine the relationships between health locus of control and stage of change to determine if such relationships existed. It may well be worth exploring whether those who have a greater internal locus of control are also more inclined to be in the preparation or action stages of renal replacement consideration.

According to Prochaska and Velicer (1997), basic research has generated a "rule of thumb" for at-risk populations in that 40% are pre-contemplation, 40% are contemplation and 20% are preparation (p. 38). These numbers were somewhat replicated by this population of renal management patients, suggesting that the TTM may have been appropriately applied to this population.

Limitations

Several limitations of this study should be addressed, beginning with the study design, which used a retrospective cross-sectional analysis of data from social work assessments as opposed to a more scientifically rigorous experimental design. The stage of change designations are based on clinical judgment and not a standardized validated measurement tool. Therefore, findings from this analysis must take that into consideration. Moreover, data was collected from one geographic area, specifically a large urban teaching hospital and more research would be necessary to see if the associations noted in this research were replicated in rural or suburban settings. Despite the limitations, several interesting findings were noted that could enhance social work assessments with ESRD populations.

Future Directions

Utilizing the stages of change as an assessment tool in brief clinical encounters can provide a valuable addition to the social worker's clinical judgment and allow for the social worker to more effectively convey the patient's psychosocial and emotional process of change within multi-disciplinary medical teams. Furthermore, understanding the stages of change allows practitioners to tailor interventions based on individual patient's emotional readiness to consider RRT. Possible future research might include a longitudinal analysis that would ascertain whether renal management patients, in particular the older renal management patients (>70 years), indeed move through the stages, or whether it is more effective as an initial assessment tool for these populations. Finally, future research should focus on the development of a standardized assessment tool and corresponding stage-based interventions based on the TTM and stage of change concepts.

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Dialysis Social Worker Training and Knowledge Regarding Kidney Transplantation

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Social workers are often a primary source of education for patients in the outpatient dialysis setting, requiring these professionals to have a broad knowledge base regarding many aspects of dialysis and the various treatment modalities. Social workers are expected to be able to competently educate their patients, yet this can only be done if they themselves have been properly trained. An investigation regarding the training social workers receive and their overall knowledge about transplantation was conducted. The findings noted that formal training was almost nonexistent and exceptionally brief. Many social workers had knowledge deficits and were unable to answer basic questions regarding the kidney transplantation process

INTRODUCTION

Social worker knowledge regarding matters such as health insurance, disability benefits, mental health, hospice care and local resources are invaluable to patients (Browne, 2006). Social workers are often a primary source of education in the dialysis clinic, which requires them to have a strong foundation of knowledge regarding many different topics. Social workers are at the forefront of issues that greatly affect the lives of patients, such as end-of-life care (Woods et al., 1999; Gwyther et al., 2005) and treatment adherence (Johnstone & Halshaw, 2003; Dobrof et al., 2000). Due to administrative and clinical responsibilities, professional roles, such as being educators and advocates for kidney transplantation, may be minimized for social workers. This is a concern for two main reasons. First, there is a large body of research noting that there is unequal access to transplantation among minorities (Furth et al., 2000; Wolfe, 2003), women (Bloembergen et al., 1997) and people with lesser socioeconomic status (Wolfe, 2006; Thomas, 2000). Second, there are numerous misconceptions that patients often have regarding the transplantation process, especially with regard to non-living donation. For example, they may believe that organs are purchased and that this is unethical, so they do not wish to pursue this treatment option. Furthermore, external sources of transplant information outside of the clinic setting, such as the Internet, are often lacking or incorrect in the material that they provide (Hanif et al., 2007). These circumstances create an environment wherein education is extremely important because patients need to be able to make informed decisions about their treatment.

Informing dialysis patients about all potential treatment modalities is not voluntary; it is a legal requirement. Federal regulation specifies that patients be advised of their suitability for transplantation (Federal Health Insurance for the Aged and Disabled, 1972). As professionals, social workers are often designated by their employer to educate patients regarding treatment modalities (DaVita Renal Healthcare, 2007). The joint Clinical Indicators for Social Work and Psychosocial Service in Nephrology Settings was created by the National Kidney Foundation's (NKF) Council of Nephrology Social Workers (CNSW) and the National Association of Social Workers (NASW). These organizational bodies specify that social workers should provide counseling and education to pre-transplant recipients and live organ donors (National Association of Social Workers, 2007). Patient education cannot be competently provided unless social workers themselves are properly trained. The following research was conducted to determine the transplant training and knowledge level of dialysis social workers.

METHOD

A panel of 3 hemodialysis social workers, ranging from 6 to 9 years of experience, was convened to formulate questions that tested basic knowledge regarding kidney transplantation. The panelists were chosen based on their expertise with patient and staff education, hemodialysis, peritoneal dialysis and organ donation. One of them had previously been a gubernatorial appointee and served on a state board that promoted organ donation and transplantation. A 10-item questionnaire was created that covered 3 core areas: patient evaluation, insurance issues, and medical risks and side effects. Each item was in multiple choice or true/false format. These questions were then matched with 10 more questions that inquired about the extensiveness of a social worker's initial training regarding transplantation, and how they evaluated their own knowledge regarding this topic. A random number generation computer program was then used to select 50 outpatient hemodialysis clinics in Georgia, Tennessee and North Carolina. The questionnaire was mailed to the social workers in these clinics along with a cover letter and self-addressed stamped envelope. They were asked to complete the

Table 1

Percentage of Social Workers Who Correctly Answered Questions

	Percent answered correctly
1. A patient can be listed for a kidney transplant at more than one hospital.	96
2. If a person obtains a kidney transplant, and their sole entitlement to Medicare is due to their kidney failure, when will their Medicare coverage terminate?	84
3. When someone is being evaluated for a kidney transplant, their specific HLA have to be identified as part of the matching process. What are HLA?	80
4. After 5 years, the majority of kidney transplants are no longer functioning.	77
5. What is the primary piece of United States federal legislation pertaining to the administration and organization of the organ transplantation process?	65
6. All solid organ transplants in the United States are matched to recipients through what organization?	61
7. What part of Medicare pays for post-transplant immunosuppressant medication once a patient is discharged from the hospital?	57
8. What is an Expanded Donor Kidney?	57
9. What are some of the common medical side effects of immunosuppressant medications?	50
10. What are the main side effects of post-transplant steroids?	15

questionnaire and return it in the envelope. Respondents were informed that their participation was voluntary and that their answers would be anonymous. Of the 50 that were mailed, 26 (52%) were returned. An analysis of the basic demographics of respondents determines that 80% of the social workers were female and they had an average of 6 years of experience in dialysis. They provided services to approximately 135 patients each (standard deviation: 42) and 92% of them worked in a for-profit clinic. Half stated that their primary clinic was in an urban area.

RESULTS

As a whole, the sample participants answered 64% of the transplant knowledge questions correctly. When the data were collapsed, those with 5 or more years working in dialysis scored only slightly better than those with 4 or less (66 vs 62%). When scores were factored together with years of experience, a mild correlation was noted with $r = 0.24$. That is to say that scores somewhat improved as years employed in dialysis increased. No significant findings were found between the 2 groups (i.e., those with less than 5 years of experience vs. those with 5 or more years of experience), $t(25) = 0.02$, *ns*. Four of the 10 questions were answered correctly by only 57% or less of the social workers. See Table 1 for the percentage of social workers who were able to answer each question correctly. When analyzed by category, questions regarding the transplant process and evaluation were more likely to be answered correctly as compared to those that focused on medical risks and side effects.

When asked if they were provided with training regarding transplantation when they were initially hired, only 3 (11.5%) of social workers stated “yes.” They received approximately 20 minutes of training on this topic and they rated the overall quality of the information to be “fair.” It is worth noting that all 3 of these social workers scored higher on the knowledge portion of the questionnaire as compared to the group average. When asked who was the primary source of patient education in their clinic regarding kidney transplantation only 8 (30.7%) of social workers identified themselves. The majority noted that this task was handled by nursing staff or the nephrologist. However, many of these social workers stated that they were in charge of completing the transplant referral paperwork (42%) and for providing written educational materials to patients (50%) regarding transplantation.

One exceptionally notable aspect of the results was that every social worker (100%) stated that they believed that they need further training regarding kidney transplantation. However, only 10 (38.4%) reported frequently reading research articles regarding transplantation, and only 1 (3.8%) reported receiving information about changes and updates regarding this topic from their employer. When asked to rate their overall knowledge level regarding kidney transplantation on a 5-point Likert Scale, the average response was “fair.” There was a low correlation (r = 0.27) between social worker scores on the questionnaire and their overall perceived knowledge level. Thus, even though most social workers believed that they had a high knowledge level regarding transplantation, this was not reflected in their actual scores on the questionnaire.

DISCUSSION

The social work roles of being an educator and advocate are vital in the dialysis setting. Patients often have questions about kidney transplantation, along with many misconceptions, which social workers need to be able to address. The results of the research with this sample show that training for dialysis social workers regarding transplantation is almost nonexistent, which is ironic because employers often identify them as being responsible for relaying transplant information to patients. Nearly 4 out of every 10 respondents could not identify the name of the organization that matches non-living organs to recipients; any discussion with patients about how the transplant waiting list functions would require this information. Years of experience did not appear to be a major factor in the sample; scores did not greatly improve when the number of years employed in dialysis increased. This is a unique finding because one might expect that knowledge would expand over time.

Over the last several years there have been efforts to improve the predialysis education that patients receive and this has greatly reduced hospitalizations and emergent care, while also increasing rates of continued employment (Golper, 2001). However, large-scale studies continue to show that many patients are still not presented with information about all of the various treatment modalities (Mehrotra et al., 2005). Fortunately, there are some clinics that have created systematic educational programs specifically regarding transplantation and these warrant further investigation to determine their impact (Malarcher, 2006).

Research has shown that there are racial and perceptual biases among physicians and patients that greatly impact access to transplantation; this research makes it particularly important that nephrology social workers join their teams in providing patients with education and information about kidney transplantation. A survey of nearly 300 nephrologists noted a general view that transplantation was less beneficial for African Americans (Ayanian et al., 2004). Another study found that African Americans were less likely to be referred for kidney transplantation or to be listed for transplantation within 18 months of initiating dialysis as compared to Caucasians (Ayanian et al., 1999). There are also many myths, misconceptions and cultural beliefs that patients may have that make them less likely to seek transplantation (Navaneethan & Singh, 2006). For example, some minority racial groups may believe that the organ-matching process is purposely and unfairly biased toward providing transplants to Caucasians. Also, there are many urban legends about people being tricked into providing donor organs, or even having them stolen. This can potentially taint a patient’s view about the safety or legality of the process. The NKF generated a press release in April 2000 to address an urban legend because it had become so rampant (NKF, 2008). On a general knowledge level, some people may not seek transplantation because they think it is a rare or experimental procedure.

Learning does not end when a social worker obtains his or her degree, it should be a constant element of continual practice. The NKF and the CNSW provide several useful online and written informational/educational materials, such as the Kidney Learning System (KLS) and Clinical Indicators for Practice, to aid in professional education. The field of transplantation is constantly evolving. New medications, surgical techniques, evaluation requirements, insurance benefits and other changes need to be known so that this information can be relayed to patients. Every social worker who completed the questionnaire believed that they needed further information regarding this topic. A unique aspect regarding dialysis social worker training is its lack of formality. Nurses, patient care technicians and machine technicians are often provided with weeks of detailed training and have to complete examinations to make sure that they have absorbed the content provided to them. Social worker training appears to be much more “word of mouth” and informal, thus an individual’s knowledge is only as valid as what is provided by the person who trains them. A study by Merighi and Ehlebracht (2004) noted a similar finding in that nearly two-thirds of employers did not provide renal-specific in-service training to their social workers. It should be noted that the deficits identified in this research were found in all types of dialysis settings—rural or urban, profit or nonprofit and across several major corporations. Thus, this is a systemic issue.

There may be a tendency for social workers to shy away from discussing the kidney transplant option with patients because they do not perceive this as being part of their role. A review of NKF/NASW guidelines contradicts this view, and it appears that many social workers are already responsible for providing written literature to patients about this topic. It is also a very limited view because social workers are often called on to deal with a myriad of educational issues regarding other aspects of dialysis, such as treatment adherence and health insurance. There is a professional and ethical responsibility to learn more about this topic so that patients can be better served.

ACKNOWLEDGEMENT

The author would like to thank all of the social workers who gave their time to participate in this study. This research was supported by a grant from the Academy of Dialysis Social Workers.

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End-of-Life Care Discussions: A Survey of Dialysis Patients and Professionals

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Bearing in mind the high mortality rate among individuals with kidney failure—in 2005, of the 485,013 individuals with End Stage Renal Disease in the United States, there were 85,790 deaths (17.6%; U.S. Renal Data System, 2007)—coupled with the confluence of complex psychological, medical, emotional, spiritual, ethical, cultural, legal and familial factors involved with the dying process, the National Kidney Foundation conducted patient and professional surveys to advance understanding of end-of-life discussions. One-hundred and eighty-two in-center hemodialysis patients and 1,202 professionals responded to surveys distributed on e-mail lists and in a clinical meeting session. Most professionals (86%) reported having end-of-life discussions with patients; however, discrepancies associated with the topics they discussed as well as with the professionals responsible for discussions were found. Of patients, 75% were receptive to having end-of-life care discussions, with more interest in talking about advance directives and pain management than other topics. Current practices are insufficient in providing patients with the necessary information to empower them to make difficult decisions about the dying process.

INTRODUCTION

The confluence of psychological, medical, emotional, spiritual, ethical, cultural, ethnic, legal and familial factors surrounding caring for our loved ones toward the end of their lives challenges health care professionals to examine existing approaches and methodologies to end-of-life care discussions. The provision of end-of-life care for people on dialysis has multiple elements (e.g., advance directives, dialysis withdrawal, do not resuscitate order [DNR], palliative care and hospice) that are best attended to at various stages of the assessment and treatment processes, with both patients and their caregivers. Many of these are frequently neglected or ignored by health care providers, creating problematic and often disturbing circumstances for patients and their loved ones that could perhaps be avoided.

Among dialysis patients 20 to 64 years old, overall mortality rates are more than 8 times greater than those found in the general Medicare population; this difference falls slightly, to 7 times higher, in patients age 65 and older. In 2005, there were 341,319 people on dialysis in the United States, with 189,709 between the ages of 20 and 64, and more than half (55%) over the age of 60. Twenty and one-half percent of people receiving dialysis treatment, or 69,990 dialysis patients, died in 2005, compared to 21% in 2004 (U.S. Renal Data System, 2006, 2007).

LITERATURE REVIEW

There is ample evidence in the literature of multidisciplinary efforts and the medical community's commitment aimed at innovative initiatives, the development of model programs and research to improve the provision of advance care planning and quality palliative and end-of-life care (Blais, 2003; Clark, 2003; Davison & Torgunrud, 2007; Pitorak & Armour, 2002; Ternestedt, Andershed, Eriksson, & Johansson, 2002). In the nephrology community, clinical practice guidelines address end-of-life issues such as withholding and withdrawing dialysis, palliative care and hospice (Holley, Davison, & Moss, 2007; Moss, 2001; National Kidney Foundation [NKF], 2006). The 2005 proposed Conditions for Coverage for End Stage Renal Disease (ESRD; Centers for Medicare and Medicaid, 2007) includes a regulation pertaining to the right of individuals to be informed about advance directives and to refuse treatment, whereas such issues were not addressed in the previous Conditions.

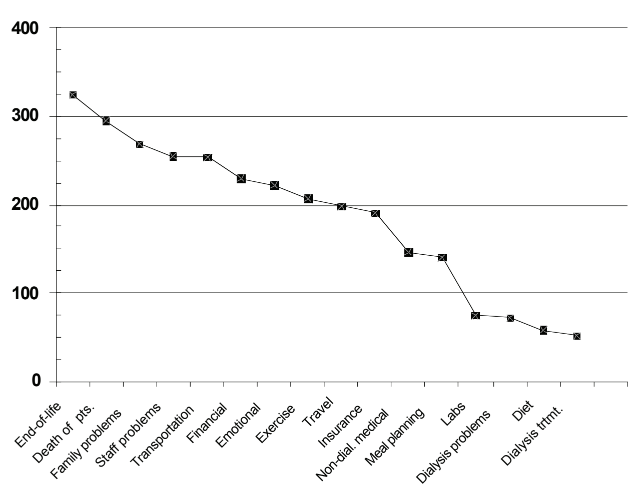
Nevertheless, much more is needed to enhance the care of people who are dying and minimize their suffering (Brody, 2003; Davison, 2002; Davison & Simpson, 2006; Henderson, 1995). All too often, life is prolonged in pain or discomfort, with medical interventions and procedures precluding an opportunity for loved ones to communicate and convey their wishes both with one another and their health care professionals. Holly (2007) points to the appropriateness of palliative care for ESRD patients and their families due to their high symptom burden, shortened survival and significant co-morbidity, and acknowledges that palliative care has much to offer toward improving the quality of dialysis patients' lives. Poor pain management, inattention to advance directives (Davison, 2006; King, 2007), underutilization of hospice care (Murray, et al., 2006), cultural differences (Mjelde-Mossey & Chan, 2007; Perry, 2005) and overall poor communication (Weiner, et. al., 2005) with patients and families about these issues are just some of the problems with established end-of-life care practices from the perspectives of patients, families, nephrology fellows and physicians that have been underscored in the literature (Davison, 2006; Hines et al., 2001; Holley et al., 2003; Moss et al., 2005; Warren et al., 2000).

Many individuals are more likely to discuss end-of-life issues with their family members than with their health care provider, and may even rely on them for making decisions (Lautrette et al., 2007). Failure to discuss end-of-life issues with families results in difficult situations in which decision makers are unprepared to make important end-of-life decisions for loved ones (Davison, 2006; ESRD Workgroup, 2001; Hines et al., 2001; Holley, 2007). Sanders et al. (2007) suggests that often all caregivers need is the opportunity to acknowledge their feelings of grief.

The Robert Wood Johnson Foundation Promoting Excellence in End-of-Life Care sponsored an ESRD Workgroup from 2000 to 2002 to improve supportive care and quality of life for ESRD patients and their families. Findings of 6 focus groups, 3 comprising dialysis patients and 3 made up of family members of deceased dialysis patients, showed that only 12% discussed end-of-life issues with the physician, and 58% did not discuss end-of-life issues at all. Even among the family members of deceased patients, many said health care providers never approached them about end-of-life issues or did so only at the very end of their loved one's life (ESRD Workgroup, 2001).

In a 2003 NKF survey about communication in dialysis facilities in which 474 in-center hemodialysis patients responded, survey respondents selected end-of-life care (*n* = 324; 68%) more often than 15 other topics as the topic they had not discussed with the health care team (Figure 1). Only 12% reported having discussions with the physician about end-of-life care, and slightly more than 12% reported such discussions with the social worker. Also significant was the low rate of end-of-life care discussions in the southeast region compared with the rest of the country, suggesting geographic differences in communication (Weiner et al., 2005).

Figure 1. Number of Patients and Topics Not Discussed: 2003 Family Focus Survey N = 474



Advance care planning and communication about end-of-life issues with health care providers have been found to be beneficial on multiple levels for both patients and their loved ones. In a study that examined the role of peer mentoring on end-of-life decision-making in 203 dialysis patients in dialysis units, Perry (2005) reported improvements in comfort discussing advance directives, subjective well-being and anxiety levels, particularly in African-American individuals. In another study, Laurette et al. (2007) points to the effectiveness of a proactive communication strategy that allows family members of intensive care unit patients to express their emotions in a family conference during which the patient's prognosis and care options were discussed. The study intervention group had more realistic expectations of the patient's outcome and reduced prevalence of anxiety and depression.

Methods

In 2007, the NKF created two surveys about end-of-life discussions in dialysis units, with the intent of furthering the kidney disease community's understanding of the perceptions of people with kidney disease on dialysis treatment, and those of their health care providers. Two versions of the survey were created; one for people with kidney disease on in-center hemodialysis (Appendix A) and one for health care professionals. The 10-item survey for people on dialysis treatment and the 7-item professionals' survey both contained multiple-choice questions, as well as open-ended questions that provided qualitative data.

NKF Patient and Family Council Executive Committee members, a group of 12 esteemed individuals affected by CKD from around the nation, who are considered outstanding spokespersons on issues impacting those with kidney disease and were consequently selected to serve as representatives on this Council, were asked to review the survey and provide input prior to dissemination to help inform the researchers as to the appropriateness of the survey questions from the patient perspective. A few noteworthy comments were provided by these reviewers:

- "The term 'end-of-life' is so blunt, I'd cry when I saw that term."
- "If this is for all folks on dialysis, I think it is a little bit unsettling to ask us about end-of-life discussions. Is there another term that can be used?"
- "More (for) the family … perhaps a lot of the questions could be pertinent to family."

This feedback afforded the NKF a deeper understanding of the gravity of the topic for people with kidney failure. To respond to the extreme sensitivity of the issue, the patient survey name and the announcement message (below) were altered to reflect these sentiments.

> When you are feeling well, you may not be thinking about changes in your health condition. Though, planning for your care toward the end-of-life is best thought about early on, when you are well and able to carefully consider important decisions. With this is mind, the National Kidney Foundation is interested in hearing your thoughts about end-of-life care for people on dialysis so that we can help improve communication and care in dialysis units. If you are either on dialysis or a professional working in a dialysis unit, you can help by completing this survey.

Due to economic considerations, it was determined that both survey groups—individuals with kidney disease and renal professionals—would be solicited initially via e-mail to facilitate a cost-effective system for survey distribution. The NKF has several constituent memberships, all of which have e-mail lists, that were believed suitable for the purpose of this survey. Prior efforts to obtain constituent feedback on relevant kidney disease topics using similar survey formats have resulted in reasonable participation.

Participants

A total of 182 individuals on in-center hemodialysis treatment responded to the survey, an estimated 6% response rate. Most respondents were fairly new to dialysis with slightly more than half on dialysis less than 2 years (53%), 18% between 3 and 5 years and 29% more than 5 years. In total, 1,202 professionals responded to this survey, an estimated 17% response rate. Respondents included both online (*n* = 1,141) and NKF 2007 Spring Clinical Meetings (CM07) session attendees (*n* = 61). Social workers comprised the largest professional respondent group (28%), followed by dietitians (27%), nurses (25%), physicians (14%), nurse practitioners and technicians (2%), eight administrators and three physician assistants. Pastors were included as potential survey respondents, however, none participated.

Measures

Survey results, tabulated using Zoomerang survey software and exported as an Excel file, were analyzed for all of the professional groups combined to evaluate the groups' perceptions as a whole, as well as for the various disciplines separately. In addition, results were cross-tabulated to provide comparisons between patients and professionals as well as among the professional groups.

Procedure

Fielding of the surveys occurred in several phases. In February 2007, an e-mail message, that explained the purpose of the survey and included a link to the survey on a Web site using Zoomerang survey technology was sent to 2,860 members (those individuals who provided an e-mail address in their membership material—10% of the total membership) of the NKF Patient and Family Council, and 288 members of the NKF "People Like Us" empowerment initiative. Some individuals may have been members of both of these listserv groups (*n* = 3,148). The listserv message with the survey link was redistributed approximately 3 months later to the same e-mail lists in an effort to recruit additional respondents.

In March, a message about the initiative with a link to the survey was posted to 3,364 NKF professional members, which included e-mail lists of the Council of Nephrology Social Workers (609), Council of Nephrology Nurses and Technicians (417), Council on Renal Nutrition (1,409) and 929 physician members. Additionally, survey announcements were sent to the 66 ESRD Kidney End-of-Life Coalition members, as this professional group was attainable electronically as well, and to more than 120 ESRD Network staff. In April, the survey was distributed to professional attendees at a CM07 session, "End-Of-Life Issues for People with Kidney Failure," for nurses and technicians, in an effort to obtain additional responses, as this group had a particularly low response rate subsequent to the initial e-mail announcements, in comparison to the other professional groups.

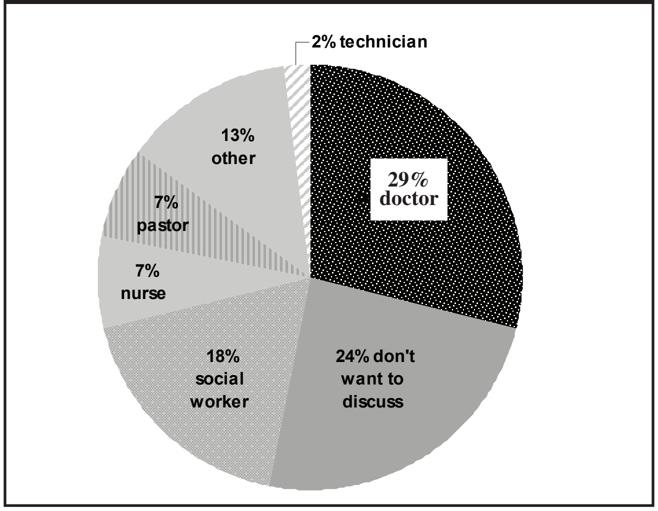
In addition, the survey was distributed to a NKF database list of 3,496 nurses and technicians in May. Some of these individuals may have received the initial survey announcement as well. Both the patient and professional surveys remained active for 5 months.

Results

Slightly more than half (54%) of all patient respondents said they have not talked about end-of-life care with a dialysis health care team member, despite the fact that more than three-fourths said they want to talk to their health care team member about end-of-life issues (76%; Figure 2). Of those who want to discuss end-of-life care, 38% wanted to talk with the doctor, followed by the social worker (24%).

Of those who had end-of-life care discussions with members of the health care team, when asked with

Figure 2. "I want to talk to the following person on my health care team about end-of-life issues." *N* **= 180**

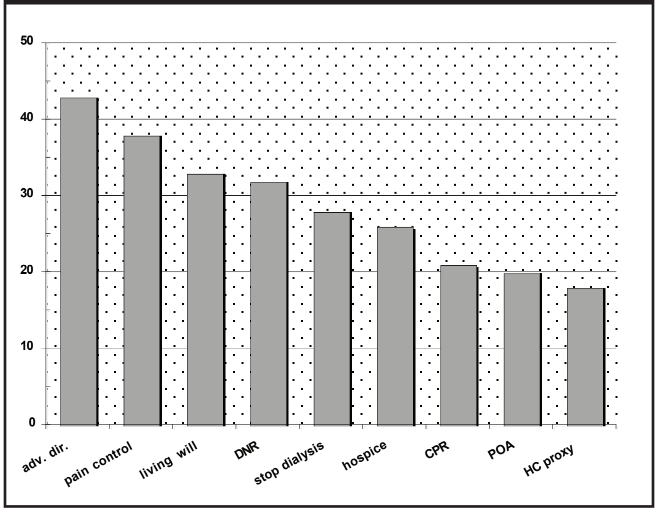


whom they talked, more respondents selected the social worker ($n = 48$), compared with 34 who said the doctor and 32 who checked the nurse. Eight individuals said they had talked with a pastor; however, there were no professionals who said that a pastor was responsible for end-of-life care discussions in their dialysis unit. It is speculated that patients who chose this option were referring to a pastor who was not a member of the dialysis health care team. Fifty-nine percent have talked with their family about their end-of-life care wishes.

Findings associated with dialysis patient tenure showed that significantly more individuals on dialysis for less than 2 years had not had end-of-life care discussions with health care team members (63%), compared with those on dialysis longer than 3 years (37%).

Respondents wanted to discuss a variety of topics associated with end-of-life care with their health care team; more respondents selected "completing an advance directive" (43%) and "pain control" (38%) compared with other topics (Figure 3).

Figure 3. "I want to talk with my health care team about the following topics."



When asked why they had not talked about end-of-life care with a team member, more than half (57%) reported that the reason was because "my health care team never talked to me about end-of-life care." Fourteen percent said they "do not feel comfortable talking about end-of-life care," and only 5% said "did not want to talk about it when I was asked." Twenty-one percent said they have had either one or two discussions, while 13% have had more than two. Five percent reported having such discussions on a regular basis.

The majority of the professionals (86%) said they have discussed end-of-life care with patients in the dialysis unit. Only 5 social workers and 9 physicians reported they had not had such discussions. Out of 11 topics associated with end-of-life care, both physicians and nurses, respectively, selected the same three topics as the ones they most often discussed: DNR (90/76%), stopping dialysis (87/87%) and CPR (82/65%). Social workers most often reported they were likely to talk about completing an advance directive (93%). Similar to the nurses and physicians, stopping dialysis (89%) was the second most frequently discussed topic according to social worker respondents. Hospice care (84%) was frequently discussed as well by social workers. Dietitians reported that they have informal discussions with patients (46%), and when they have had talked with patients it was most often about stopping dialysis (46%) and hospice care (30%).When all professional groups are combined, the topics most often discussed were stopping dialysis (77%), hospice care (65%), DNR (62%) and completing an advance directive (61%).

The topics patients wished to discuss differed markedly from those that doctors said they have discussed with patients (Figure 4). For example, while most patients chose advance directives as the topic they wish to discuss, and social workers also selected this as the topic they have talked about most often with patients, doctors said they are most likely to talk about DNR with patients. One might speculate that discussions about advance directives are perceived by doctors to be more within the scope of the social worker's role. Moreover, because most doctors talk with patients "when they have a major health crisis" (60%), it is logical that the majority of discussions would be about DNR.

While stopping dialysis is top among subjects both doctors and social workers talk about, only 15 patients reported they would like to discuss this topic. Patients

Figure 4. Comparing what patients want to discuss with topics professionals have discussed by percentage

most often selected advance directives (43%) and pain control (38%) as the two topics they wished to talk about. Less than half of the total professionals (48%) said they have discussed pain control with patients. Sixty-four percent of physicians have discussed pain control with patients.

When asked to identify the one person most often assigned to the task of end-of-life care discussions in the dialysis unit, slightly more than half of professional respondents said it was the social worker. However, only a third of physicians identified the social worker as the responsible individual. Half of the physician group said the doctor is the professional identified to have these discussions. Conversely, only 12% of the social workers said it was the doctor, while 68% believed the social worker is the person responsible for end-of-life care discussions.

Many professionals were not certain who was primarily responsible for this task (e.g., "I don't know," "Unsure, assume the physician, social worker and private clergy if appropriate," "No formally identified person," "Unknown," and in some instances there was variation as to who was assigned to this task, "Usually the social worker but sometimes the nurse.") Several professional respondents explained that discussions were a multidisciplinary or team effort of many health care members, or occurred with two professionals in partnership. Many said that nutrition issues such as tube feeding, fluid management, use of supplements and withdrawal of nutritional support were often topics of discussion. Funeral information, spiritual and religious issues, quality of life, fears about dying and suicide were additional topics professionals discussed with patients.

The timing of discussions was sometimes arbitrarily determined (e.g., "Discuss as the topic comes up," "Varies depending on the situation," "When patients are not doing so well," "Patient says something that helps start talking," "When they start talking in a hopeless fashion," or "As deemed appropriate.")

More than one-third of professional respondents said they do not have discussions because patients "do not usually want to talk to me about end-of-life care," however, only 5% of patients concurred with this perception. Instead, more than half of patient respondents explained "my health care team never talked to me about end-of-life care."

DISCUSSION

A valuable lesson learned from this survey of end-of-life care discussions in dialysis units is that health care providers need to be mindful of the tremendous sensitivity of the issues. Although the majority of patient respondents did not support the opinions of those individuals who were disturbed by end-of-life discussions, extreme care must be taken when approaching patients about such matters. More focused communication within the context of an organized program with skilled staff will likely help enhance facilitation of end-of-life discussions and ensure proper attention to the topics patients wish to discuss. Professionals identified to assume the task should receive appropriate training to increase their comfort level with the issues, enabling them to adequately manage the myriad of emotions and psychological responses that may unpredictably arise.

LIMITATIONS

Patient surveys were available for online completion only, thereby producing a select respondent group: individuals who were either proficient in accessing and comprehending the survey format or had someone available to assist them. Had the survey design allowed for respondents to complete it in a written format, this would have produced a more generalizeable respondent group. The survey design neglected to comprise respondent demographics, such as geography, gender, age, education level, etc. The availability of such data would have provided a richer and more instructive view of the survey topic, allowing for more comprehensive examination. Because of the insufficient response from dialysis technicians, perhaps due to the unavailability of contact information and/or database list capabilities, we were unable to derive valuable perspectives from this professional group that is central to the care of individuals receiving dialysis treatment. As the survey was intended to evaluate the perspectives of dialysis patients and professionals exclusively, the researchers decided to exclude family members from this effort.

Nevertheless, understanding the role of the family/caregiver is integral and their input should be sought.

CONCLUSION

Misconceptions exist about patients' willingness to talk, as well as the subjects they wish to discuss. Consensus is lacking among health care team members regarding which individual in the dialysis unit is primarily responsible for end-of-life care discussions and when discussions should occur. The establishment of a structure and process in which health care professionals are trained, and discussions are initiated earlier on, targeting the subjects patients wish to discuss, e.g., advance directives and pain management, may help to cultivate an environment in which having end-of-life care discussions is an expectation.

In a culture such as this, random decision making regarding end-of-life discussions will be alleviated, and the pathway will be paved for the most difficult of discussions about topics, such as stopping dialysis and DNR. Patients will be encouraged to explore issues with their health care professionals, empowering them with the knowledge they need to make important choices with their loved ones about the dying process.

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APPENDIX A

Discussions About Care for the End-of-Life Survey: People on Dialysis

Thinking about changes in health status is often very difficult. With this is mind, the National Kidney Foundation is interested in hearing your thoughts about end-of-life care for people on dialysis so that we can help improve communication and care in dialysis units. If you are on dialysis, you can help by completing this survey ***(only people on dialysis should complete this survey)***. It will take about 5 minutes to answer all of the questions. Your time can help you and others. Thank you very much!

1. Are you on dialysis?

☐ Yes
☐ No **(If no, please STOP and do not complete the rest of the survey.)**

2. How long have you been on dialysis? (Check only one answer.)

☐ Less than 6 months
☐ Between 6 months and 1 year
☐ 1 to 2 years
☐ 3 to 4 years
☐ 5 to 10 years
☐ More than 10 years

3. I have had discussions about end-of-life care with the following members of my dialysis unit health care team. (Check all that apply.)

☐ Dietitian
☐ Doctor
☐ Nurse
☐ Pastor
☐ Social Worker
☐ Technician
☐ I have not had discussions about end-of-life care
☐ Other: ____

4. In these discussions about end-of-life care, we talked about the following topics. (Check all that apply.)

☐ Caring for loved ones/children if I am unable to do so
☐ Completing an advance directive (this includes stating my wishes about my health care and treatment at the end-of-life)
☐ Completing a Living Will
☐ CPR (Cardiac Pulmonary Resuscitation)
☐ DNR (Do Not Resuscitate)
☐ Hospice care
☐ Pain control
☐ Selecting a Power of Attorney
☐ Selecting a Health Care Proxy
☐ Stopping dialysis
☐ Had informal discussions (no specific topic)
☐ I did not have discussions about end-of-life care
☐ Not sure
☐ Other: ____

5. How many discussions have you had about end-of-life care with your health care team? (Check only one answer.)

☐ 1
☐ More than 2
☐ None
☐ 2
☐ Not sure

APPENDIX A (Cont'd)

6. When did you talk about end-of-life care with your health care team? (Check <u>all</u> that apply.)

☐ When I started dialysis
☐ Sometime during the first year after I started dialysis
☐ More than a year after I started dialysis
☐ We talk about end-of-life care on a regular basis
☐ When I had a major health crisis
☐ I never had a discussion about end-of-life care with my health care team
☐ Other: ____

7. I did not have a discussion about end-of-life care because: (Check <u>all</u> that apply.)

☐ My health care team never talked to me about end-of-life care
☐ I did not want to talk about end-of-life care when I was asked
☐ I do not feel comfortable talking about end-of-life care
☐ I <u>have</u> talked about end-of-life care with my health care team
☐ Other: ____

8. I want to talk to the following person on my health care team about end-of-life care. (Check the <u>one</u> person you would most like to have this discussion with.)

☐ Dietitian
☐ Doctor
☐ Nurse
☐ Pastor
☐ Social Worker
☐ Technician
☐ I do not want to talk about end-of-life care
☐ Other: ____

9. I want to talk to my health care team about the following end-of-life care topics: (Check <u>all</u> that apply.)

☐ Caring for loved ones/children if I am unable to do so
☐ Completing an advance directive (this includes stating my wishes about my health care and treatment at the end-of-life)
☐ Completing a Living Will
☐ CPR (Cardiac Pulmonary Resuscitation)
☐ DNR (Do Not Resuscitate)
☐ Hospice care
☐ Pain control
☐ Selecting a Power of Attorney
☐ Selecting a Health Care Proxy
☐ Stopping dialysis
☐ Had informal discussions — no specific topic
☐ I did not have discussions about end-of-life care
☐ Not sure
☐ Other: ____

10. I have talked about my end-of-life care wishes with my family. (Check only <u>one</u> answer.)

☐ Yes ☐ No ☐ Not sure

CNSW ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION 2008 SPRING CLINICAL MEETINGS

MASTERING HEMODIALYSIS TO REVERSE PATTERNS OF MISSED AND SHORTENED TREATMENTS

Jessica Cabness[1], Cindy Miller[2], Kristin Martina[2.1]University of South Florida, School of Social Work, Tampa, FL, [2]USF Dialysis Center, Tampa, FL

Missed and shortened hemodialysis (HD) treatments, often developing in the first months of HD, put patients at greater risk for fluid overload and hospital utilization. Missed treatments also impact dialysis center revenues. Mindful of the social worker's (SW) dual ethical responsibility to patients and employing agencies, we tested the hypothesis that a nephrology SW intervention would be more effective in reversing missed and shortened treatments than traditional educational approaches (i.e., having patients watch an instructive video during treatment or receiving nurse chair-side instruction). In a convenience sample, *treatment-resistant* patients (n=14) were admitted to the SW intervention group receiving four 90-minute psychoeducation classes ("Mastering Hemodialysis") over four weeks. To avoid researcher bias, nursing staff identified patients receiving the video education (n=7) and patients receiving the nurse teaching (n=7) as the comparison group. Baseline measures of missed and shortened treatments were obtained for participants in both groups and compared at three months. Baseline measures for the *treatment-resistant* patients were also compared at six months from the start of the SW intervention to measure adherence to HD treatment over time. Baseline and post-test measures of scores on the SF-36v2 and the Beck Depression Inventory (BDI)—FastScreen were compared. While patients receiving the video and nurse chair-side instruction showed some improvement in the number of missed and shortened treatments when measured at three months from project startup, the SW intervention group demonstrated sustained improvement when missed and shortened treatments were compared at three and six months. The SW intervention group scored higher at post-test in all self-reported health function domains on the SF-36v2 than did the patients receiving video instruction, and lower on the BDI—Fast Screen than did the comparison group. "Mastering Hemodialysis" classes are urged to truncate patterns of missed and shortened treatments. Multi-site randomized replication is exhorted.

NEPHROLOGY SOCIAL WORK SALARIES, PATIENT CASELOADS, AND IMPLICATIONS FOR CKD CARE IN THE UNITED STATES

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1, 3. Council of Nephrology Social Workers
2. Boston University

In 2007, The Council of Nephrology Social Workers (CNSW) executed an online salary survey for social workers in all settings (CKD, dialysis, transplantation and administration). The anonymous information will help improve the understanding of the current salaries, benefits, licensure status, education level, number of dialysis units covered, scope of transplant social work services provided, and caseloads of nephrology social workers, along with related implications for chronic kidney disease patient care. 1,747 social workers completed the entire survey over several months in 2007. The annual salary ranged from $20,502-$83,803 for dialysis social workers and $37,981-$84, 989 for transplant social workers. Full time social work caseloads in dialysis units were as high as 425 patients. We posit that social workers with high caseloads, that cover more than one dialysis unit, and that have to drive great distances to their workplaces are less able to provide adequate assistance to CKD patients and their families in ameliorating psychosocial barriers to optimal care and outcomes.

CNSW ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION 2008 SPRING CLINICAL MEETINGS

QUALITY OF LIFE (QOL) AND LIFE SATISFACTION OF PATIENTS UNDERGOING MAINTENANCE HEMODIALYSIS THRICE A WEEK IN INDIA

Sujata Rajapurkar, Jincy Vergese, Muljibhai Patel Urological Hospital, Nadiad, Gujarat, India

Maintenance hemodialysis (MHD) thrice per week is life saving however expensive treatment. To save on expenses patients opt for and nephrologists recommend twice instead of thrice a week hemodialysis in an effort to save cost.

The present study is aimed at finding out quality of life and life satisfaction in our patients on MHD and to compare these parameters among 45 stable patients on MHD for minimum of 6months. 20 patients were on twice a week (Group A) compared to 25 patients thrice a week (Group B). Quality of life was assessed by SF-36 v2 Health survey. Life satisfaction was assessed by life satisfaction scale (LSS) by National Psychological Corporation, India.

	PCS	MCS	LSS
A	33.7±8.03	34.15±13.41	39.35±6.08
B	41.24±9.4	41.12±15.19	42.32±4.18
p	0.004*	0.059	0.03*

PCS: Physical Component Summary,
MCS: Mental Component Summary

3/20(15%) in Group A had >50 and 7/25(28%) had >50 score by SF-36 survey. 9/20(45%) among Group A had low life satisfaction score whereas 5/25(15%) among Group B had low life satisfaction. None in both groups achieved high life satisfaction score.

Twice weekly MHD gives poor QOL & life satisfaction.

CNSW Research Grants Program

Purpose: The purpose of the CNSW Research Grants Program is to further knowledge of psychosocial factors in chronic kidney disease (CKD) and to enhance clinical social work intervention with dialysis and transplant patients/families.

Areas of Interest

1.) Research on psychosocial factors in CKD

2.) Clinical practice research projects focusing on social work assessment and treatment strategies

3.) Educational programs to enhance patient and family understanding of CKD treatment

4.) Pilot or demonstration projects which have broad applicability to nephrology social work

Eligibility: Grant applicants must meet the following eligibility requirements:

A. Membership in CNSW

B. Minimum of 2 years' nephrology social work experience (CMS Guidelines)

C. Approval of the department head or director of research facility

D. Residence in the United States or its territories

E. "Qualified social worker" as stated in ESRD Regulations

Grant Requirements: Each grant recipient is responsible for:

- Conducting the project as set forth in the proposal
- Obtaining IRB approval 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 grant
- Submitting progress reports and a final report within 60 days of the end of the grant year
- Presenting a paper at the NKF Spring Clinical Meeting
- Submitting a manuscript based on the results to *The Journal of Nephrology Social Work*

Funding: CNSW annually requests grant monies from NKF. One or more grants will be awarded from the $24,000 budgeted in the next fiscal year. Grant 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.

Funds may not be used for the purchase of equipment. Budgets must allocate $750 for airfare and one night's accommodation to enable grantees to present their research at the 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.

How to Apply: If you are interested in preparing a proposal, please submit a letter of intent to the CNSW Research Grants Program, National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016 by October 15, 2008. The letter of intent must include the following:

- Name of the person and organization submitting the proposal
- Address, telephone number, fax number and e-mail address of lead investigator
- Title of the project
- Approximate cost
- Brief abstract—under 250 words—that includes a description of the project goal and how it relates to the purpose of CNSW research

Upon receipt of your letter of intent, NKF-CNSW will forward the CNSW application packet to you.

Review Schedule

October 15, 2008	Letter of intent due
December 1, 2008	Proposals due
January/February	Review by CNSW Grants Coordinator and CNSW Research Grants Committee
March	Awards announced
July 1	Approved projects begin operation

Further Information: For more detailed information or to be put in contact with a research "mentor" contact Jeff Harder by e-mail: **jharder@u.washington.edu**