The Journal of Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of nearly 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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The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The next issue of the journal will contain 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
- Kidney Transplant
- Pediatric Issues
- End-of-Life Concerns
- Sleep Disorders
- Sexual Functioning
- Aging and Gerontological Issues
- Disaster Preparedness
- Comorbid Illnesses
- Home Dialysis Modalities
- Professional Roles
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- HIV/AIDS
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- Ethics

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The Journal of Nephrology Social Work (JNSW) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate 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 Editor 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.

Paper and Type. Hard copy manuscripts should be submitted on standard-sized (8 1/2” x 11”), white paper. Both hard copy and electronic versions should confirm to the following guidelines: Text should be double-spaced, set in 12-point type (preferably Times New Roman) and have 1-inch margins along all sides of every page. Starting with the title page, pages should be numbered in the upper, right-hand corner and should have a running head in the upper left-hand corner. The running head should be a shortened version of the manuscript's title and should be set in all uppercase letters. The first line of every paragraph in the manuscript should be indented, as should the first line of every footnote.

Order of the Manuscript Sections

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

Title Page. The manuscript's title page should contain the title of the manuscript and the name, degree, and current affiliation of each author. Authors are generally listed in order of their contribution to the manuscript (consult the *Publication Manual of the American Psychological Association, Fifth Edition,* the APA style guide, for exceptions). The title page should also contain the complete address of the institution at which the work was conducted and the contact information for the primary author. A running head (a shortened version of the manuscript's title) should be set in the upper left-hand corner of the page, in all uppercase letters. Page numbering should begin in the upper right-hand corner of this page. With the exception of the page numbers and running heads, all text on the title page should be centered.

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.

References. The reference list should begin on a new page, with the word "References" centered at the top of the page. Entries should be listed alphabetically, according to the primary author's last name, and should conform to APA style (see sample references provided). Running heads and page numbers should continue from the text. Do not use software functions that automatically format your references. This can cause the references to be lost when the manuscript is formatted for typesetting.

Appendixes. Each appendix should begin on a new page and should be double-spaced. Running heads and page numbers should be continued from the text of the manuscript. The word "Appendix" and the identifying letter (A, B, C, etc.) should be centered at the top of the first page of each new appendix. Running heads and page numbers should continue from the references.

Author Note. If there is an author note, it should begin on a new page with the words "Author Note" centered at the top of the page. Each paragraph should be indented. Running heads and page numbers should continue from the last appendix. Consult the APA style guide for further details on the structure of an author note.

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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.

Figure Captions. Each figure in the manuscript must have a caption, formatted as follows:

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 Disease.*

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 Disease, 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 Disease, 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.
- Most other file formats (Powerpoint, JPG, GIF, etc.) are not of sufficient resolution to be used in print. The resolution for all art must be at least 300 dpi. A hard copy of each figure should accompany the files.
- In addition to the images that appear in your word processing file, it is important to send the images as individual files too. These images should be grayscale (black and white) only. They should be TIF or EPS file formats only.
- We would prefer a printed copy of the final version of the manuscript to be sent to verify contents.
- A copyright form signed by at least one of the authors.

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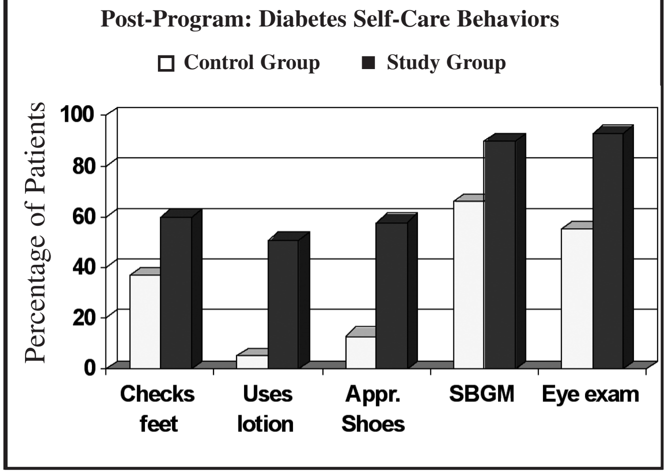
CONTENTS

Erratum to: "Diabetes: The Dialysis Outcomes Practice Patterns Study Results and Innovative Patient Care Program," *JNSW*, May 2007, Volume 26, pp. 41-44.

We would like to thank Margaret Eichleay, MPH, Epidemiologist at Arbor Research Collaborative for Health, for bringing to our attention the fact that **Table 1** reported inaccurate percentages in three categories: checks feet, uses lotion, and wears appropriate shoes. The correct percentages for these categories and an amended table are presented below.

Checks feet	Control Group, 37% Study Group, 60%
Uses lotion	Control Group, 5% Study Group, 51%
Wears appropriate shoes	Control Group, 13% Study Group, 58%

Self-Care Behaviors



Prevalence, Predictors and Correlates of Non-Adherence to a Hemodialysis Regimen: A Review of the Literature

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A review was conducted of the literature on prevalence, predictors and correlates of adherence to the therapeutic regimen in adults receiving hemodialysis (HD). Searches were conducted on Medline, PsycINFO and CINAHL from the years 1950 to 2007. Articles selected for this review met the following inclusion criteria: subjects were adult HD patients, at least one predictor or correlate of adherence was studied and at least one adherence outcome was included. Sixty-nine articles were included in the review. Rates, predictors and correlates of non-adherence (NA) varied widely. Young age and smoking were the only variables that consistently predicted NA. Suggestions for practice and future research are described.

INTRODUCTION

End-stage renal disease (ESRD) has steadily increased in prevalence in the United States (U.S. Renal Data System, 2005). In-center hemodialysis (HD) is the most common treatment, with 90.7% of those with ESRD choosing this modality in 2003 (U.S. Renal Data System, 2005). Adherence to the long-term, complex regimen leading to successful HD treatment has been shown to be challenging with rates of non-adherence (NA) from 2 to 50% (Leggat et al., 1998) and as high as 86% (Bame et al., 1993). The World Health Organization defines adherence 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, p. 13). Successful HD therapy requires adherence to dialysis treatment, diet, medication and fluid goals. Diet intake of protein, sodium and potassium must be limited because excretion by the kidney is compromised. Medications must be taken to treat ESRD and associated morbidities. For example, phosphate binders are routinely administered to enhance intestinal phosphate excretion because normal kidney excretion is limited. Fluids must be restricted because the failing kidney cannot excrete excess fluids. The Dialysis Outcomes and Practice Patterns Study revealed that NA significantly increases the risk of hospitalization and mortality (Saran et al., 2003). NA with dialysis treatments, diet, medications and fluids may result in nausea, weakness, metabolic disturbances, bone demineralization, pulmonary edema, cardiovascular damage and death (Bame et al., 1993; Chan & Greene, 1994). The purpose of this study was to conduct a review of the literature of prevalence, predictors and correlates of adherence to the HD regimen in adults receiving HD.

METHODS

Searches were conducted on Medline, PsycINFO and CINAHL databases using the key words *hemodialysis*, *haemodialysis*, *fluid adherence*, *fluid compliance*, *diet adherence*, *diet compliance*, *medication adherence*, *medication compliance*, *adherence* and *compliance*. Medline was searched from 1950 to 2007, CINAHL from 1982 to 2007, and PsycINFO from 1967 to 2007. Articles written in English were evaluated for inclusion. Finally, ancestry searches were conducted on all eligible studies. Articles selected for this review met the following inclusion criteria: subjects were adult HD patients ages 18 years and older, at least one predictor of adherence was studied using a correlation statistic, and at least one adherence outcome was studied.

The following information was abstracted from each article: author, year, purpose, sample size, age, gender, ethnicity, time on dialysis, country of study, theoretical framework, methods, single- or multi-center study and measures. In addition, the following questions were answered from each study’s results: Is smoking, social support, depression, ethnicity, education level, time on dialysis or age a predictor or correlate of NA? What is the diet NA rate? The following outcomes were extracted from the studies: What was the level of serum phosphorus NA? What was the level of serum calcium NA? What was the level of serum albumin NA? What was the level of serum potassium NA? What is the fluid NA rate? What was the level of NA to interdialytic weight gain (IDWG)? What was the level of NA to treatment

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as measured by KT/V? Was the sample adherent to treatment as measured by missed or shortened dialysis treatments? Was the sample adherent to medications? What other demographic predictors were found? What cognitive and affective predictors were found? What other predictors were found? Due to space constraints, Appendix A (page 21) presents the following information collected from the studies: author, year, purpose, sample size, age, gender, ethnicity, time on dialysis, country of study, theoretical framework, methods, single- or multi-center study and measures. A table of the other measures is available from the corresponding author upon request.

RESULTS

Sixty-nine articles were included in the review. The sample sizes ranged from 15 (Zetin et al., 1981) to 11,422 participants (Hecking et al., 2004). The mean age ranged from 24 years (Chan & Greene, 1994) to 70 years (Berman et al., 2004). The percentage of male subjects ranged from 30% (Brady et al., 1997) to 81% (Kimmel et al., 1996). Slightly less than half of the studies ($n = 34$) reported subject ethnicity with many different ethnicities represented. One study included all African Americans (Long et al., 1998), one all Turkish subjects (Taskapan et al., 2005), one all Chinese subjects (Lee & Molassiotis, 2002) and one all Japanese subjects (Takaki & Yano, 2006). The average number of months on dialysis ranged from 6.7 months (Wenerowicz et al., 1978) to 140.58 months (Wiebe & Christensen, 1997). Seventy-one percent of the studies ($n = 49$) were conducted exclusively in the United States. Four of the studies were published in the 1970s, 12 in the 1980s, 34 in the 1990s and 19 thus far in the 2000s.

Most studies used a mixed design with the predictor variables typically obtained using a cross-sectional, survey approach while the outcome measures were collected in a longitudinal fashion (averaged over several months). Only 16 articles mentioned using a theory-based intervention. The most frequently used theoretical model was the Health Belief Model, used by six studies. Forty-six (66%) were multi-center in nature.

Gender and NA

Twenty-nine reports examined the relationship between gender and NA. Of them, 17 (59%) reported no statistically significant correlation between gender and NA. Of the remaining 41% ($n = 12$) that found a significant relationship, the findings were varied with both men and women adherent and non-adherent to outcomes.

Smoking and NA

Of the 69 studies, 6 examined the relationship between smoking and NA. All six studies found that smoking was correlated with poor adherence outcomes. Kugler and colleagues (2005) found that smoking was significantly correlated with diet NA frequency and degree and fluid NA frequency and degree. Leggat and colleagues (1998) discovered that smokers were more likely to be non-adherent than nonsmokers for skipped and shortened treatments, IDWG and elevated phosphorus levels. Saran and colleagues (2003) noted that smokers were 1.53 times more likely to miss treatments, 1.43 times more likely to have increased IDWG, 1.10 times more likely to have elevated phosphorus levels and 0.96 times more likely to have elevated potassium levels. Similarly, Takaki and colleagues (2003) found that smoking was correlated with IDWG ($p = 0.0015$). Unruh and colleagues (2005) noted that smoking was correlated with missed treatments ($p \leq 0.01$) while Kutner and colleagues (2002) discovered that smoking was correlated with missing treatments ($p = 0.01$), shortening treatments ($p = 0.02$) and non-adherent phosphorus levels ($p = 0.002$).

Social Support and NA

Of the 21 studies that examined the relationship between social support and NA, most of the studies (62%; $n = 13$) found a significant correlation with lower social support associated with poorer adherence outcomes. One study found mixed results with frequency of fluid NA correlated with social support ($p = 0.005$), while diet NA was not substantiated (Kugler et al., 2005).

Depression and NA

Eleven studies conducted analyses on the correlation between depression and NA. Of them, six found that depression was not significantly correlated with NA while five found significant correlations. For example, Saran and colleagues (2003) in the DOPPS study found that those who were depressed were 1.62 times more likely to skip treatments ($p < 0.05$) and 1.22 times more likely to shorten treatments ($p < 0.05$). Depression was not significantly correlated with IDWG, elevated phosphorous levels or elevated potassium levels. Taskapan et al. (2005) studied a sample of 40 Turkish subjects and found 65% were depressive, anxious or had a somatoform disorder. In those with depression or a somatoform disorder, IDWG was significantly higher than that of patients without these disorders ($p < 0.05$). Conversely, Berman et al. (2004), using the Beck Depression Inventory, did not find a statistically significant correlation between depression and the number of missed or shortened dialysis sessions during a 4-month period. Similarly, Oka and Chaboyer (2001) found no correlation between depression, neurotic tendencies and somatic symptoms, measured by the Mental Health and the Somatic Symptoms Scales, and dietary behavior, measured by the Dietary Behavior Scale, in a sample of 325 Japanese subjects.

Ethnicity and NA

Eighteen of the studies described relationships between ethnicity and NA. Half ($n = 9$) of the studies found a statistically significant association; the others did not. The studies that examined ethnicity most frequently reported differences between Caucasians and African Americans. Those conducted outside of the United States did not typically examine the influence of ethnicity on NA.

Education and NA

Twenty-three of the studies examined the relationship between educational preparation and NA with 21 of 23 documenting no statistically significant relationship between educational preparation and NA. Two studies found a statistically significant relationship (Christensen et al., 1997a; Weed-Collins & Hogan, 1989).

Time on Dialysis and NA

Time on dialysis was examined in 27 of the studies with 11 of 27 finding a significant correlation between time on dialysis and NA; however, 16 of 27 found no significant correlation. Of those finding significant correlations ($n = 11$), seven showed positive correlations between time on dialysis and NA outcomes (i.e., those on dialysis for longer periods of time were more non-adherent). For example, Kugler and colleagues (2005) found that time on dialysis was significantly correlated with degree of diet ($p = 0.003$) and fluid ($p = 0.015$) NA, but not with frequency of diet and fluid NA. Saran and colleagues (2003) noted that those with longer time on dialysis were 1.05 times more likely to shorten treatments, 1.07 times more likely to have IDWG and 1.03 times more likely to have elevated potassium. Saran et al. (2003) also found that a longer time on dialysis was not significantly correlated with shortened dialysis treatments or elevated phosphorus levels. Takaki and colleagues (2003) discovered that higher potassium ($p = 0.0009$) and phosphorus levels ($p = 0.0093$) were correlated with duration of dialysis. On the other hand, 4 of the 11 found negative correlations between time on dialysis and NA (i.e., those on dialysis for shorter periods of time were more non-adherent; Berman et al., 2004; Bollin & Hart, 1982; Boyer et al., 1990; Gordon et al., 2003).

Age and NA

Of the 40 studies that examined the correlation between age and dialysis outcomes, 28 found a significant correlation. Of those 28, 25 found that younger age was correlated with greater NA to dialysis outcomes such as missed or shortened dialysis treatments, potassium and phosphorus blood levels, diet and fluid balance. Only two articles determined that older age was associated with increased NA. One of the 28 found that age was correlated with IDWG ($p < 0.05$), but the correlation disappeared when education was controlled for (Chan & Greene, 1994).

Diet NA Rate

Twelve of the studies identified diet NA rates. The rates varied dramatically from 14% (Cummings et al., 1982) to 74% (Chan & Greene, 1994). Measures of diet NA rates varied as well. For example, Cummings and colleagues (1982) used 2 to 3 weeks of serum potassium levels abstracted from the medical records to measure dietary NA, while Chan and Greene (1994) used potassium and IDWG to measure dietary NA. Measurement in other reports varied as well. Using an author-developed dietary knowledge questionnaire, Durose et al. (2004) found a self-reported 35% NA rate with one or more dietary restrictions. Kugler et al. (2005) used the diet and fluid NA self-report questionnaire to document a dietary NA rate of 81.6% for the previous 14 days. Lee and Molassiotis (2002) used both blood levels and self-report to measure dietary NA. They found 35.5% NA as measured by both serum potassium and phosphorus levels. Self-report over the previous 7 days was documented at a similar rate of 34% using a Likert scale with two questions. Leggat and colleagues (1998), using a single dietary measure of serum phosphorus of greater than 7.5 mg/dL to measure dietary NA, found a rate of 22% NA.

Phosphorus Levels and NA

Twelve studies examined serum phosphorus level and NA. Phosphorus levels were calculated and presented in various ways. Durose et al. (2004) found that 69% achieved a serum phosphorus level of 5.88 mg/dL (1.9 mmol/L). Lee and Molassiotis (2002) found that 43.5% had a mean phosphorus level of 6.8 mg/dL (2.19 mmol/L). Leggat et al. (1998) found 22% had a phosphorus level greater than 7.5 mg/dL. Similarly, Saran et al. (2003) found a rate of phosphorus greater than 7.5 mg/dL in 13.7% of subjects. Hecking et al. (2004) found that 11.7% were greater than 7.5 mg/dL. Several studies presented mean phosphorus levels that ranged from 4.87 (Kugler et al., 2005) to 6.78 (Lee & Molassiotis, 2002). Although Taskapan et al. (2005) focused on differences in adherence between people with and without psychiatric disorders, the mean phosphorus level was 4.7 mg/dL for those with psychiatric disorders and 5.2 mg/dL for those without.

Several research groups examined the correlation between phosphorus and NA. For example, Kugler et al. (2005) found that a mean phosphorus level of 4.87 mg/dL was positively correlated with NA ($p = 0.002$) and also positively correlated with frequency of fluid NA ($p = 0.0001$). Zrinyi et al. (2003) examined phosphorus level as a predictor for adherence and found that it did not significantly contribute to predicting patients' compliance behaviors (b = –0.019; $p = 0.867$).

Calcium Levels and NA

A single study examined serum calcium levels and NA (Taskapan et al., 2005). Taskapan et al. (2005) examined 40 HD patients to determine the impact of psychiatric disorders on fluid restrictions, nutritional status and quality of life. Those with psychiatric disorders had a mean calcium level of 8.7 mg/dL, whereas those without psychiatric disorders had a mean calcium level of 8.8 mg/dL. The presence of a psychiatric disorder did not predict adherence with diet as measured by serum calcium.

Potassium Levels and NA

Six studies described potassium NA rates but comparison of results is difficult because various normal ranges were used. NA rates ranged from 10.8% (serum potassium >6 meq/L) to 29.1% (goal serum potassium average <5.59 mg/dL; Lin & Liang, 1997; Saran et al., 2003). One study found that serum potassium level was negatively correlated with active coping ($p = 0.0075$; Takaki et al., 2003), while another study found no relationship between serum potassium and NA with IDWG (Sensky et al., 1996).

Albumin Levels and NA

Several studies described correlations between serum albumin levels and NA. For example, Kugler et al. (2005) found that serum albumin level positively correlated with frequency and degree of diet NA ($p = 0.0001$ and $p = 0.0001$, respectively) and frequency and degree of fluid NA ($p = 0.015$ and $p = 0.0001$, respectively). Similarly, Zrinyi and colleagues (2003) discovered that albumin significantly contributed to predicting patients' adherence behaviors (b = 0.102; $p = 0.003$). Taskapan et al. (2005) found that those with psychiatric disorders had a mean level of 3.5 mg/dL, whereas those without psychiatric disorders had a mean albumin level of 3.65 mg/dL. Another study described mixed findings. Unruh and colleagues (2005) showed no significant difference in serum albumin between those who skipped dialysis treatments and those who did not. They also found no significant difference between those with phosphate levels higher than 5.5 mg/dL and those with a phosphate level of 5.5 mg/dL or lower. However, they did find a statistically significant difference in albumin between those with potassium 5.0 mg/dL or lower (albumin 3.62 mg/dL ± 0.36) and those with potassium higher than 5.0 mg/dL (albumin 3.68 mg/dL ± 0.30). Hecking et al. (2004) compared practice patterns in dialysis prescription across countries and found that pre-dialysis albumin ranged from 3.73 g/dL in the United Kingdom to 4.14 g/dL in Germany. No efforts were made to correlate albumin with adherence.

Rate of Fluid NA

Fluid NA rates were reported in 12 studies with ranges from 10% (>5.7% IDWG; Leggat et al., 1998) to 71% (Chan & Greene, 1994). Hecking et al. (2004) noted that relatively high IDWG values were observed in Italy and France, with lowest in United Kingdom and Germany. Taskapan et al. (2005) found that those with psychiatric disorders had significantly higher IDWG ($p < 0.05$) than those without psychiatric disorders.

Medication NA Rate

Six studies calculated medication NA rates. Curtin et al. (1999) found that the medication NA rate was 52% for antihypertensive medications and 70% for phosphate binders as measured by electronic monitoring. Long et al. (1998) showed that medication adherence was 0.11 to 1.00 (M = 0.57; SD = 0.28) for 15 subjects as measured by pill counts. Cummings et al. (1982) recorded high medication NA rates at 70%. Two studies evaluated predictors of medication NA with mixed results (Christensen & Smith, 1995; Christensen et al., 1994). Lower levels of conscientiousness were correlated with NA to medications ($p < 0.05$) while vigilance and dialysis type were not associated with medication NA.

Rates of Missed or Shortened Dialysis Treatments

Thirteen studies described rates of missed or shortened dialysis treatments. Rates of missed dialysis treatments ranged from 0.6% (Hecking et al., 2004) to 38%

(Gordon et al., 2003). Various lengths of time were used to calculate missed or shortened treatments. For example, Hecking et al. (2004) followed treatments for 1 month while Gordon et al. (2003) used 3 months for their analysis.

When shortened treatment rates were examined, Unruh et al. (2005) documented the lowest rate of 1.28% while Gordon et al. (2003) documented the highest rate of 92%. Unruh et al. (2005) examined medical records retrospectively for an average of 938 days for the group.

Other Predictors of Adherence

Varied psychosocial predictors of NA were examined in these studies using diverse instruments. Several predictors were examined in sufficient numbers of studies to warrant discussion here, including locus of control, knowledge and satisfaction. Locus of control was examined in 9 studies. Locus of control may assist in identifying how individuals perceive the link between their behavior and resulting outcomes. Those with an external locus of control believe that outcomes are not influenced by their specific behaviors, while those with an internal locus of control believe that they are responsible for their own well-being. The hypothesis then follows that those with higher levels of external locus of control might be more non-adherent. Four studies found no correlation between external locus of control and NA behaviors (Blackburn, 1977; Bollin & Hart, 1982; Brown & Fitzpatrick, 1988; Pang et al., 2001), four studies found significant correlations between external locus of control and NA (Lin & Liang, 1997; Poll & De-Nour, 1980; Schneider, 1992; Zetin et al., 1981), and one found mixed results with external and internal locus of control correlating with NA (Wenerowicz et al., 1978).

Several studies examined knowledge as a predictor of adherence in HD patients. Durose and colleagues (2004) found that knowledge of dietary restrictions and the medical consequences of NA were predictive of dietary compliance but in the opposite direction expected; those with better phosphorus knowledge and better knowledge about medical complications from NA were less likely to be adherent to phosphorus ($p = 0.03$ and $p = 0.002$, respectively) and those with better knowledge about medical complications from NA were also less likely to be adherent to sodium and fluid restrictions ($p = 0.008$).

Two studies correlated knowledge and NA with results in the direction expected. Chan and Greene (1994) examined dietary adherence in a group of young HD patients (mean age 24 years) and found that those who could identify their sodium regimens had a lower average IDWG that those who could not ($p = 0.05$). The researchers also noted that perceived difficulty in following fluid restrictions was correlated to IDWG ($p < 0.01$). Katz and colleagues (1998) studied 56 HD patients in the United States with an average age of 60.5 years using the health belief model as a framework. They used a composite objective score of NA that incorporated serum potassium, serum phosphorus and IDWG. The researchers found that lower knowledge was correlated with NA ($p = 0.02$) and this association was moderated by age (younger patients were more knowledgeable and more adherent). However, when NA was measured by self-report, no correlation was noted between knowledge scores and NA.

Finally, two studies found no correlation between knowledge and adherence. Lee and Molassiotis (2002) studied dietary knowledge in Chinese HD patients and found no statistically significant correlations between dietary knowledge and adherence. Greater number of perceived barriers ($p < 0.05$), lower residual urine output ($p < 0.01$), more hours on HD ($p < 0.01$), working ($p < 0.01$) and having food prepared by someone else ($p = 0.051$) increased diet and/or fluid NA. In a U.S. study, Weed-Collins and Hogan (1989) found no correlations between knowledge of phosphate-binding medications, health beliefs (susceptibility, severity, benefits) and adherence. The researchers noted that the number of barriers identified by the patient as interfering with his/her ability to adhere was correlated with adherence ($p < 0.05$). The most frequently cited reasons for NA were forgetting by 50% and being away from home by 43% of the respondents.

Patient satisfaction has also been examined as a predictor of medication NA in several studies with mixed results. Kovac and colleagues (2002) found a statistically significant correlation between patient satisfaction and perception of caring shown by staff and patient albumin level. However, no correlation was found between patient satisfaction and phosphorus or KT/V, nor was a correlation found between patient perception of ancillary staff (nurses, dietitians, social work, technical workers) and adherence. However, patient satisfaction with the nephrologist was correlated with better dialysis attendance and total time on dialysis adherence. In another study by Kimmel and colleagues (1995), lower satisfaction with life, less disease severity and depression were correlated with phosphorus NA ($p < 0.05$ for all). However, Unruh et al. (2005) found no significant associations between quality of life, social support, patient satisfaction and other maladaptive health behaviors and serum phosphorus adherence.

DISCUSSION

The existing research literature on prevalence, predictors and correlates of NA in adult HD patients was reviewed. The number of published articles increased dramatically each decade, indicating attention to this important challenge in adult HD patients.

Study sample sizes varied dramatically. No study reported conducting a power analysis to determine appropriate sample size. Several studies cited limitations in interpreting results due to small numbers of NA outcomes. The samples were typically obtained using a convenience sampling technique, which may limit the ability to make generalizations from these findings. This limitation is balanced by the demographic diversity across the studies. The studies included both younger and older adults. However, as the age at which patients initiating HD increases and those on the therapy live longer, studies of older HD patients' NA issues including NA prevalence, predictors and outcomes will be increasingly important to study.

Only about a quarter (23%) of the studies reported using a theoretical framework. Efforts to develop effective interventions studies to move the science in the area forward must be based on strong theoretical foundations. The reports included varied cultural groups, which provide a foundation for identifying and comparing predicators across cultures. Developing and testing culturally appropriate adherence interventions will also be enhanced with this strong foundational knowledge base (Russell, 2006).

The most frequently used methods involved a longitudinal approach to outcome data collection, over 2 to 6 months, while using a cross-sectional, survey approach to obtain the predictor data. While this approach is appropriate for studies examining stable predictors such as demographic information, this design does not account for possible variation in the unstable predictor variables such as depression, knowledge or satisfaction, which may change over time.

NA rates indicate that NA among HD patients is indeed a concerning problem. Diet NA rates were 14 to 74%, fluid NA from 10 to 71%, medication NA rates as high as 70%, missed dialysis treatments from 0.6 to 38% and shortened treatments with the broadest rate range of 1 to 92%. These broad ranges are likely influenced by the inconsistent use of NA outcome measures.

The link between certain demographic variables such as educational level and NA were clearly not supported in this review of the literature. Other results indicated mixed findings. Gender, time on HD, ethnicity and depression were not consistent predictors. Because many of the studies performed simple regression analyses, and not the more powerful multiple regression techniques, interaction effects between variables may have been overlooked.

Predictors that can be influenced by intervention provide the most value to health care providers for improving adherence. Identifying predictors may also assist in tailoring interventions to individual needs and expectations (Dec, 2006). The behavioral and effective predictors of smoking and low levels of social support were both correlated to HD NA. Nephrology social workers can incorporate this knowledge from our literature review into their clinical work. One suggestion would be implementing a smoking cessation program, which may indirectly improve non-adherent behaviors. Implementing smoking cessation interventions may improve both non-adherent behaviors. Another suggestion would be to focus on developing a network of support for the adult HD population. Interventions to address depression, either through brief therapy or groups, might be beneficial in improving adherence outcomes.

CONCLUSION

In summary, this group of 70 articles describes the prevalence, predictors and correlates of NA in adult HD patients. Demographic predictors, except for younger age, do not provide guidance to health care providers for early identification of those at risk for NA. Methodological issues such as inconsistent use of measures of predictor and outcome variables make comparison across studies difficult. Future research is clearly guided by this review. Future studies should be theory-based, use valid and reliable instruments, be planned with adequate power and use standardized outcome measures.

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APPENDIX A

Article Information

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
Bame et al., 1993, Texas	To investigate the prevalence of NA behavior and examine variation in adherence with diet, fluid and medications	*N* = 1230; mean age: 59; age range: 18–90; average length of time on dialysis: NR	47.10% male; 43.4% African American; 14.4% Hispanic; 0.6% Asian	Multi-site cross-sectional, descriptive with longitudinal component	Demographic information	Diet NA: BUN (<100 mg/dL), K (<6.5), Phos med NA: Phos (6.0 or less), IDWG (<1 kg/day)
Basta, 1981, Mid-Atlantic United States	To compare differences in self-concept components between adherent and non-adherent HD patients	*N* = 80; mean age: NR; age range: NR; average length of time on dialysis: NR	NR	Multi-site descriptive, comparative	Background information form, Tennessee Self-Concept Scale, Rosenberg's Global Self-Esteem Scale	Composite score of fluid overload, IDWG, hypertension, K, BUN and missed dialysis treatments
Berman et al., 2004, United States	To describe the relationship between religiosity and with life and medical care satisfaction, social support, depression and adherence	*N* = 74; mean age: 54; age range: 21–84; average length of time on dialysis: 42 months	42% male; 89% African American	Single site survey	Hoge Intrinsic Religiosity Scale, Karnofsky Performance Scale (functional ability), Beck Depression Inventory, Multidimensional Scale of Perceived Social Support, Satisfaction with Life Scale, Satisfaction with Medical Care, Coping Behavior Scale, Schwartz Outcome Scale (satisfaction with life and mental status)	NA (number of missed dialysis treatments and shortened sessions in 4 months)

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
Blackburn, 1977, Texas	To examine predictors of adherence to HD	*N* = 53; mean age: 42.55; age range: 7–72; average length of time on dialysis: 18.6 months	64% male; 60% Caucasian	Single-site longitudinal, descriptive	Demographic information; questionnaire to assess cognitive understanding of diet, fluid and medication instructions; Rotter Internal-External Scale; staff perceptions	K (3–5 mEq/L), phos 3.5–5.0 mg/100 mL, IDWG (>4 lb) for 3–14 months prior to survey
Bollin & Hart, 1982, Iowa	To examine the relationship between health beliefs, locus of control and relative health valuing and dietary adherence	*N* = 30; mean age: 51; age range: 21–76; average length of time on dialysis: 37.4 months	57% male; ethnicity NR	Multi-site cross-sectional, descriptive with longitudinal component; theory: health belief model	Health beliefs: Standardized Compliance Questionnaire, Health Locus of Control Scale, Relative Health Value	Fluid: 24-hour urine and IDWG calculation every fifth dialysis for 5 months, then scored; K: 6-month period scored, urine excretion also included; recall of dietary habits: scored
Borkman, 1976, United States	To identify the usefulness of staff's estimates of patients' intelligence levels or level of understanding of a restriction predicting dietary adherence	*N* = 661; mean age: NR; age range: 83% between 25–54; average length of time on dialysis: 22% on dialysis 18 months or more	75% male; ethnicity NR	Multi-site secondary data analysis; data from 1967	Staff-completed questionnaire regarding patient understanding of restrictions, estimated patient intelligence; physicians and nurses completed most questionnaires	Staff rated patients on water, salt and protein intake adherence

Boyer et al., 1990, New York	To explore the relationship between demographic variables, social support, situational factors and adherence	*N* = 60; mean age: NR; age range: NR; average length of time on dialysis: NR	71% male; 71% Caucasian	Multi-site cross-sectional, descriptive with longitudinal component	Social support: author-developed survey; patient's perception of social support, negative feed-back, absence of social support, family support, family report of negative feelings, staff-reported medical support, demographic and situational factors	Serum phos and BUN (5 months); K (13 dialysis treatments)
Brady et al., 1997, United States	To examine the impact of fluid adherence efficacy expectations, fluid adherence outcome expecta-tions and fluid adherence motivation on IDWG	*N* = 50; mean age: 61; age range: NR; average length of time on dialysis: 54.83 months	30% male; 74% African American	Multi-site descriptive, correlational; theory: Bandura's self-efficacy theory	Marlowe-Crowe Social Desirability Scale Short-Form, Fluid Adherence Self-Efficacy Questionnaire, Fluid Adherence Motivation Rating	IDWG (weekend)
Brown & Fitzpatrick, 1988, London	To examine psychosocial variables on dietary adherence	*N* = 41; mean age: 52; age range: NR; average length of time on dialysis: 81.6 months	51% male; ethnicity NR	Single-site cross-sectional, descriptive with longitudinal component	Multidimensional health locus of control, family support and the acceptance of dialysis questionnaires, patient's self-reported dietary adherence	IDWG, K, BUN; composite score calculated

Author, Year, Location	**Purpose**	**Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis**	**Sex (% male) and Ethnicity (% most prevalent ethnicity)**	**Methods**	**Predictor Measures**	**NA Measure**
Chan & Greene, 1994, Pennsylvania	To describe dietary adherence in young chronic HD patients	*N* = 31; mean age: 24; age range: 15–30; average length of time on dialysis: 50.4 months	52% male; 71% Caucasian	Multi-site longitudinal survey	Dietary sodium and K-Hartman and Becker survey of factors associated with adherence, food frequency questionnaire	IDWG <2 kg; K <5.5 mEq/L
Christensen et al., 1990, Utah	Tested predictive interactive effects of person and treatment on self-reported depression and laboratory measures of adherence with both dietary and fluid-intake restrictions	*N* = 53 (34 in-center and 19 home HD patients); mean age: 42.37; age range: NR; average length of time on dialysis: in-center: 53.33 months, home: 115.74 months	In-center, 62% male; home, 42% male; ethnicity NR	Single-site cross-sectional, descriptive with longitudinal component	Krantz Health Opinion survey, behavioral involvement subscale, Beck Depression Inventory	Fluid: IDWG >4.5 lb averaged over 25 dialysis sessions; diet: serum K >5.5 mEq/L
Christensen et al., 1992, Utah	To examine the effects of social support and illness-related physical impairment on adherence	*N* = 81; mean age: 51.9; age range: NR; average length of time on dialysis: 75.3 months	51% male; ethnicity NR	Multi-site cross-sectional, descriptive with longitudinal component	Social support: family relationship index of the Family Environment Scale; physical impairment: Sickness Impact Profile	IDWG >4.5 kg averaged over 25 dialysis sessions; serum K >5.5 mEq/L

Christensen et al., 1994, Utah	To examine the effects of dialysis type and coping style (information vigilance and active coping) on diet and medication adherence	*N* = 86; 52 in-center HD patients and 34 CAPD patients; mean age: in-center HD 50.14, CAPD 46.49; age range: NR; average length of time on dialysis: 75.90 months (in-center), 67.89 months (CAPD)	In-center, 52% male; CAPD, 53% male; ethnicity NR	Single-site	Coping: internal and powerful others health locus of control subscales from the Multidimensional Health Locus of Control Scale and behavioral involvement and information preference subscales of the Krantz Health Opinion Survey and Miller Behavioral Styles Scale; depression: Beck Depression Inventory	Phos (≤2.0 mmol/L); K (3.5–6.5 mmol/L); IDWG (≤4% of dry body weight)
Christensen et al., 1995, Iowa	To examine the relationship of coping to adherence in two different types of stress situations (controllable and uncontrollable)	*N* = 57; mean age: 56.91; age range: NR; average length of time on dialysis: 73.02 months	44% male; ethnicity NR	Multi-site, cross-sectional, descriptive with longitudinal component	Coping: Ways of Coping Inventory; participant appraisals of the stressful encounter	Fluid NA-IDWG >2.5 kg averaged over 12 dialysis sessions
Christensen & Smith, 1995, Utah	To examine the association of the NEO Five-Factor Inventory to adherence	*N* = 72; mean age: 46.39; age range: NR; average length of time on dialysis: 73.11 months	54% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component	NEO Five-Factor Inventory (extraversion, agreeableness, conscientiousness, neuroticism, openness to experience)	Diet: K; medication: phos

Author, Year, Location	**Purpose**	**Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis**	**Sex (% male) and Ethnicity (% most prevalent ethnicity)**	**Methods**	**Predictor Measures**	**NA Measure**
Christensen et al. 1997a, Iowa	To describe how the relationship between self-monitoring and adherence is mediated by the tendency of high monitors to use avoidant coping strategies; control was also examined as a mediating variable	*N* = 51; mean age: 56.72; age range: 21–78; average length of time on dialysis: 51.28 months	59% male; ethnicity NR	Multi-site, cross-sectional, descriptive with longitudinal component; theory: monitoring process model	Monitoring dimension of the Miller Behavioral Styles Scale; A trait anxiety scale of the State-Trait Anxiety Scale; distancing and escape-avoidance subscales of the Ways of Coping Inventory; perceived control measured by Multidimensional Health Locus of Control Scales and a question about situation-specific control	Medication NA: phos >5.5 mEq/L; dietary NA: serum K <5.5 mEq/L
Christensen et al., 1997b, Iowa	To examine the role of cynical hostility and powerful others health locus of control expectancies in predicting regimen adherence	*N* = 48; mean age: 56.2; age range: 23–88; average length of time on dialysis: 65.09 months	54% male; ethnicity NR	Multi-site, cross-sectional, descriptive with longitudinal component	Patient expectations about health care providers was measured by the Multidimensional Health Locus of Control Scales; cynical hostility was measured by the Cook-Medley Hostility Scale	Fluid NA: IDWG >2.5 kg averaged over 12 dialysis sessions; diet and medication NA: phos >5.5 mg/dL

Cummings et al., 1982, Michigan	To examine the relationships of health beliefs, knowledge about the treatment regimen, regimen complexity, family and provider support and personal characteristics to adherence	*N* = 116; mean age: 54.8; age range: 21–74; average length of time on dialysis: 29 months	54% male; 50% Caucasian	Multi-site, cross-sectional, descriptive with longitudinal component	Survey on health beliefs, knowledge of regimen, knowledge of treatment instructions, regimen complexity, support from family and friends, support from medical staff and family problems	Med adherence: serum phosphorus (2–4 months before survey); diet: K (2–3 weeks), IDWG (2–3 weeks); patient self-report of adherence to outcomes
Curtin et al., 1999, United States	To describe the prevalence, severity, patterns and predictors of noncompliance with prescribed medications among HD patients	*N* = 135; mean age: 63.2; age range: 28–89; average length of time on dialysis: 15% on dialysis <1 year; 22% on dialysis for >5 years	47% male; 45% African American	Single-site, longitudinal descriptive	Demographic information from medical record	Medication adherence: electronic monitoring, pill counts, self-report (Wisconsin Brief Medication Questionnaire)
Cvengros et al., 2004, United States	To examine the joint role of perceived restriction of control and individual differences in preference for control in predicting adherence to the HD regimen	*N* = 49; mean age: 55.6; age range: NR; average length of time on dialysis: 60.8 months	55% male; ethnicity NR	Multi-site, observational; surveys	Preference for Information and Preference for Behavioral Involvement subscales, Krantz Health Opinion survey, six-item tool developed for this study	IDWG >2.5 kg averaged over 12 dialysis sessions

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
De-Nour & Czaczkes, 1972, Israel	To explore personality factors as determinants of NA	*N* = 43; mean age: NR; age range: NR; average length of time on dialysis: NR	66% male; ethnicity NR	Multi-site, longitudinal descriptive	Psychiatric exam, personality traits	Excellent: IDWG not above 500 g, predialysis K never >6 mEq/L, predialysis BUN steady; good: IDWG 500–1000 g, K ≤6 mEq/L, BUN steady with some jumps; fair: IDWG 1,000–1,500 g, K 6–6.8 mEq/L; some abuse: IDWG 2,500–2,000 g, K near 7.0 mEq/L; great abuse: IDWG >2000 g; K >7 mEq/L
DeOreo, 1997, Ohio	To correlate the SF-36 with survival, hospitalization and dialysis attendance adherence	*N* = 1000; mean age: 58.2%; age range: NR; average length of time on dialysis: NR	50% male; 23% Caucasian	Multi-site, historical, prospective	Medical Outcome Study Short Form (MOS SF-36)	Serum albumin, BUN, variable volume, Kt/V, protein catabolic rate, skipping treatments (≥2 dialysis treatments per month)
Durose et al., 2004, United Kingdom	Examine dietary knowledge of K, phos sodium, fluid restrictions and complications in relationship to knowledge of dietary compliance	*N* = 71; mean age: NR; age range: 44% were 18–54; 56% were 55–84; average length of time on dialysis: 51% were on dialysis ≤2 years	58% male; 86% Caucasian	Single-site survey	Author-developed dietary knowledge questionnaire	Phos (≤2.0 mmol/L); serum K (3.5–6.5 mmol/L); IDWG (≤4% of dry body weight)

Friend et al., 1997, United States	To determine whether patients' evaluations (attributions) of their past fluid adherence would also predict changes in fluid adherence from one time to another; whether health beliefs would act as a motivational force to reduce fluid adherence over time; and whether negative emotions (depression, trait anxiety, anger) would influence fluid adherence over time	*N* = 39; mean age: 55.8; age range: 20–77; average length of time on dialysis: 39.6 months	74% of the original 50 subjects were male; 78% were Caucasian	Multi-site, longitudinal, descriptive correlational	Attribution (three questions); Health Belief (three questions)	IDWG: for the preceding 8 weeks and 4 months later; calculated the percentage of 24 sessions at each time point in which each subject gained more than 3 kg was calculated
Gordon et al. 2003, Ohio	To develop reasons for shortened or skipped treatments	*N* = 168; mean age: 55; age range: 23–88; average length of time on dialysis: 48 months	73% male; 72% African American	Multi-site, cross-sectional study, survey	Author-developed survey reasons for shortened or skipped dialysis treatments	Shortened or skipped dialysis treatments over 3 months
Hecking et al., 2004, France, Germany, Italy, Spain and United Kingdom (DOPPS also used Japan and United States, but they were not analyzed for this article.)	To evaluate the practice patterns of HD facilities and patients across continents, focusing on dialysis prescription, adherence and nutrition	*N* = 11,422 patients from 101 units, targeted 4,591 patients for study; mean age: 59.5; age range: 57–61; average length of time on dialysis: NR	62% male; ethnicity NR	Multi-site, prospective, observational study	Medical record review for co-morbidities, lab values, quality of life variables, medication, hospitalization history, vascular access history	Adherence (missing and shortening dialysis, hyperkalemia, hyperphosphatemia, high IDWG, malnutrition)

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
Hilbert, 1985, United States	To investigate the relationship of social support to adherence	*N* = 26; mean age: 46.9; age range: 22–75; average length of time on dialysis: 54 months	35% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component	Social support: support question-naire with 18 items from the Inventory of Socially Supportive Behaviors	Self-report on diet, medications and fluid for total adherence score
Hitchcock et al., 1992, United States	To examine the effects of stress on dietary adherence	*N* = 57; mean age: 57.6; age range: 26–81; average length of time on dialysis: NR	49% male; 67% African American	Single-site, cross-sectional, descriptive with longitudinal component	Schedule of Recent Events, Weekly Stress Inventory, Social Support Questionnaire	Diet: K and BUN (baseline 2 weeks before predictor survey and outcome 2 weeks after)
Katz et al., 1998, United States	To assess knowledge of disease and its impact on NA	*N* = 56; mean age: 60.5; age range: NR; average length of time on dialysis: 30 months	54% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component; theory: health belief model	Kidney Disease Questionnaire	K, phos, IDWG composite score; self-report of adherence

Kimmel et al., 1996, United States	To investigate the relationship between psychological and social factors to adherence in new HD patients (<6 months)	*N* = 99; mean age: 54.5; age range: NR; average length of time on dialysis: NR	81% male; 92% African American	Multi-site	Beck Depression Inventory, Illness Effects Questionnaire, Multidimensional Scale of Perceived Social Support, Satisfaction with Life Scale, Psychologic Adjustment to Illness Scale, Karnofsky Scale, ESRD Severity Coefficient, Syadic Adjustment Scale	Shortened or skipped dialysis treatments, total time (shortened and missed) for 5 month, K, phos, IDWG, anthropometry, protein catabolic rate, Kt/V for 3 months
Kimmel et al., 1998, United States	To determine the contribution of compliance and psychosocial factors to patient survival	*N* = 295; mean age: 54.6; age range: 19–84; average length of time on dialysis: 56.6 ± 51.9 months	71% male; 90.1% African American	Multi-site, prospective, longitudinal	ESRD Severity Coefficient; nutritional and dialytic parameters: protein catabolic rate and Kt/V, dialyzer type, serum albumin, arm and circumference arm muscle area; Beck Depression Inventory, Cognitive Depression Index; Multidimensional Scale of Perceived Social Support; Illness Effects Questionnaire; Satisfaction with Life Scale	Percent time compliance (shortening dialysis); percent attendance (skipping dialysis); total time compliance (shortening and skipping)

Author, Year, Location	**Purpose**	**Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis**	**Sex (% male) and Ethnicity (% most prevalent ethnicity)**	**Methods**	**Predictor Measures**	**NA Measure**
Kimmel et al., 1995b, Washington, DC (Aspects of QOL in HD Patients [same study as Kimmel, 1995a])	To assess the relationship between several QOL measures and patient adherence	*N* = 149; mean age: 54.4; age range: 23–83; average length of time on dialysis: NR	67% male; 93% African American	Multi-site, longitudinal, descriptive	Depression: Beck Depression Inventory, Cognitive Depression Index, Perception of Illness Effects Scale; social support: Multidimensional Scale of Perceived Social Support; patient satisfaction with marital/partner situation: Dyadic Adjustment Scale	Shortened or skipped dialysis treatments, total time (shortened and missed) for 5 months, serum K, serum phosphorus, IDWG, anthropometry, protein catabolic rate, Kt/V for 3 months
Kimmel et al., 1995a, Washington, DC (same study as Kimmel, 1995)	To assess whether different behavior adherence measurements have similar relationships with psychological and medical parameters; to investigate the relationship of adherence to dialysis unit, gender, psychological factors and social support	*N* = 149; mean age: 54.4; age range: 23–83; average length of time on dialysis: NR	67% male; 93% African American	Multi-site, longitudinal, descriptive	Depression: Beck Depression Inventory, Cognitive Depression Index, Perception of Illness Effects Scale; social support: Multidimensional Scale of Perceived Social Support; patient satisfaction with marital/partner situation: Dyadic Adjustment Scale	Shortened or skipped dialysis treatments, total time (shortened and missed) for 5 months, serum K, serum phosphorus, IDWG, anthropometry, protein catabolic rate, Kt/V for 3 months

Kovac et al., 2002, Washington, DC	To determine whether associations exist between patient satisfaction with care, depression and social supports with prescribed HD treatment	*N* = 79; mean age: 52.8; age range: 20–85; average length of time on dialysis: 57.7 months	59.50% male; 93.7% African American	Multi-site, cross-sectional, survey	Karnofsky, Beck Depression Inventory, social support, patient satisfaction and lab values	Skipping or shortening treatments, K and phos
Kugler et al., 2005, Belgium and Germany	To describe the prevalence and predictors of NA with diet and fluid restrictions in European HD patients	*N* = 916; mean age: 67; age range: 19–91; average length of time on dialysis: 47 months	52.90% male; ethnicity NR	Multi-site, cross-sectional, descriptive with longitudinal component; self–report; medical records	Dialysis Diet and Fluid NA questionnaire	IDWG, phos, K, albumin, Kt/V
Kutner et al., 2002, Georgia	To determine predictors of NA	*N* = 119 HD, *N* = 51 PD; mean age: NR; age range: NR; average length of time on dialysis: NR	NR	Multi-site	Perceived health status: physical and mental component summary scores of the Medical Outcomes Study Short Form; smoking status: self-report; perceived global self-health care and control over future health: National Health Interview Survey; depression: Primary Care Evaluation of Mental Disorders Brief Patient Health Questionnaire; other psychosocial variables: disease-specific scales from the Kidney Disease Quality of Life Short Form instrument	Missed appointments, shortened treatments (≥10 minutes during past 4 weeks); phos >7.5 mg/dL (3-month average)

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
Lee & Molassiotis, 2002, China	To understand how dietary knowledge and health beliefs affect compliance	*N* = 62; mean age: 46; age range: 22–73; average length of time on dialysis: 11.5 months	50% male; 100% Chinese	Single-site, cross-sectional study, descriptive correlational design; theory: health belief model	Knowledge scale (author-developed); health belief scale	Medical record for K, phos, IDWG
Leggat et al., 1998, Iowa	To better describe the demographics of NA patients and the survival differences between compliant and non-compliant patients	*N* = 6,251; mean age: 57.8; age range: NR; average length of time on dialysis: 44.4 months	49.70% male; 39% African American	Multi-site, sample was taken from two studies of the U.S. Renal Datea System: Case Mix Adequacy Study (CMAS) and Dialysis Morbidity and Morality Study (DMMS)	Used data from the two studies of the U.S. Renal Data System	Skipping dialysis sessions, shortening sessions, IDWG, phos
Lin & Liang, 1997, Taiwan	To examine health locus of control and adherence	*N* = 86; mean age: 55.1; age range: 26–86; average length of time on dialysis: 42.1 months	45% male; ethnicity NR	Multi-site, cross-sectional, descriptive with longitudinal component; theory: social learning theory-locus of control	Demographic questionnaire, the Multidimensional Health Locus of Control Scale, Multi-Method Compliance Assessment	Multi-method adherence assessment: IDWG (4 weeks prior), K (4-month average), phos (4 months prior), all three converted into an adherence score; nurses rated patients on a scale, patients' self-report

Long et al., 1998, Southeastern U.S. inner-city dialysis unit	To identify relationships between demographic factors, psychosocial characteristics and medication adherence rates in older patients receiving HD	*N* = 26; mean age: 70; age range: 65–83; average length of time on dialysis: 100% on dialysis for ≥1 year or longer	36% male; 100% African American	Single-site, descriptive correlational; theory: King	Iowa Self-Assessment Inventory (psychosocial variables)	Pill counts
Oka & Chaboyer, 2001, Japan	To examine the influence of self-efficacy and other factors on dietary behaviors	*N* = 325; mean age: 57.2; age range: NR; average length of time on dialysis: 88.8 months	7% male; Japanese	Multi-site, cross-sectional, descriptive with longitudinal component, survey; theory: Bandura's theory of self-efficacy	Dietary management self-efficacy, self-repressive behavior, dialysis acceptance, mental health, family support, staff support, character surveys	Dietary Behavior Scale Survey
Pang et al., 2001, China	To determine psychosocial correlates of fluid NA	*N* = 92; mean age: 51.36; age range: 22–79; average length of time on dialysis: 79.08 months	39% male; Chinese	Multi-site, cross-sectional, descriptive with longitudinal component survey	Center for Epidemiological Studies Depression Scale, Multidimensional Health Locus of Control Form C Scale, Social Support Questionnaire, Short Form Scale, Socio-Demographic Scale	IDWG (>0.9 kg/day had poor fluid adherence; those with ≤0.9 kg/day had good adherence)

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
Poll & De-Nour, 1980, Israel	To investigate the relationship between locus of control and diet adherence	*N* = 40; mean age: NR; age range: NR; average length of time on dialysis: NR	45% male; ethnicity NR	Multi-site, cross-sectional, descriptive with longitudinal component	Rotter's locus of control	Excellent: IDWG ≤500 g, predialysis K never >6 mEq/L, predialysis BUN steady; good: IDWG 500–1,000g, K ≤6 mEq/L, BUN steady with some jumps; fair: IDWG 1,000–1,500 g, K 6–6.8 mEq/L; some abuse: IDWG 2,500–2,000 g, K near 7.0 mEq/L; great abuse: IDWG >2,000 g, K >7 mEq/L 3 months prior to study
Rocco & Burkart, 1993, North Carolina	To determine adherence to HD medical regimen	Mean: 231 patients (31,599 HD sessions scheduled); mean age: 61.9; age range: 24–91; average length of time on dialysis: NR	52% male; 67% African American	Single-site, longitudinal, descriptive	None	Missed appointments; shortened treatments

Rorer et al., 1988, United States	To examine the impact of nursing verbal interactions on patient adherence	38 patients, 13 nurses; mean age: 53.2 (patients); NR (nurses); age range: 30–67 (patients); NR (nurses); average length of time on dialysis: 45.3 months	Patients, 46% male; nurses, 100% female; ethnicity NR	Single-site survey	Nurses' verbal interactions with patients	IDWG (4 weeks prior to study)
Rosenbaum & Smira, 1986, Israel	To determine if patient's self-evaluation of past adherence and efficacy expectations are associated with adherence	*N* = 53; mean age: NR; age range: 20–68; average length of time on dialysis: NR	59% male; ethnicity NR	Multi-site, cross-sectional; theory: Mischel's social learning analysis of delayed gratification	Learned resourcefulness: Rosenbaum's Self-Control Schedule; Process-regulating cognitions: past adherence, efficacy expectations, health beliefs, coping with the illness	IDWG
Saounatsao, 1999, Athens, Greece	To evaluate the relationship between response to illness and adherence	*N* = 60; mean age: 49.4; age range: NR; average length of time on dialysis: 50.4 months	53% male; ethnicity NR	Multi-site quantitative; theory: Orem	Pritchard Response to Illness questionnaire	IDWG: 72 values <4.4 lb, K: 3.3–5.5 meq/L, phos 3.5–5.0 mg/dL, the degree of adherence was evaluated along a 4-point scale

Author, Year, Location	**Purpose**	**Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis**	**Sex (% male) and Ethnicity (% most prevalent ethnicity)**	**Methods**	**Predictor Measures**	**NA Measure**
Saran et al., 2003, United States, Japan, France, Germany, Italy, Spain, United Kingdom	Describe the magnitude, distribution and predictors of NA	*N* = 7,676; mean age: 60.3; age range: NR; average length of time on dialysis: 38.4 months	57.50% male; 19.8% African American; 5.4% Hispanic	Multi-site, observational, prospective; medical records	Same measures used in the DOPPS study	Skipping dialysis sessions, shortening sessions, IDWG >5.7% of body weight, phos >7.5 mg/L, K >6.0 mEq/L
Schneider et al. 1991, New York	To examine the role of cognitive and emotional variables in fluid NA, symptomatology and stress	*N* = 50; mean age: 55.8; age range: 20–77; average length of time on dialysis: 39.6 months	74% male; 78% Caucasian	Multi-site, longitudinal descriptive	Depression: Beck Depression Inventory; anxiety: Speilberger Trait Anxiety Scale, Anger-Siegal Multidimensional Anger Inventory; cognitive measures: Locus of Control of Behavior Scale; compliance perceptions	IDWG for 8 weeks (24 sessions) prior to the surveys; Somatic Symptom Distress Scale; Dialysis Stress Scale

Schneider, 1992, Baltimore, Maryland	To examine the ability of health locus of control to predict diet adherence	*N* = 137; mean age: 51.1; age range: NR; average length of time on dialysis: 26.4 months	54% male; 56.9% African American	Multi-site survey	Multidimensional Health Locus of Control	Phos
Sehgal et al., 1998, Ohio	To examine the relationship between delivered amount of dialysis and barriers	*N* = 721; mean age: 62; age range: 20–89; average length of time on dialysis: 39.6 months	51% male; 51% Caucasian	Multi-site, cross-sectional, descriptive with longitudinal component	Systolic and diastolic blood pressure, treatment time missed due to low blood pressure, nursing intervention for low blood pressure, interdialytic symptoms, nursing intervention for patient symptoms	Delivered dialysis: Kt/V, NA: minutes of prescribed treatment time missed due to these barriers
Sensky et al., 1996, United Kingdom	To explore the psychosocial and cognitive factors associated with diet and fluid adherence	*N* = 45; mean age: 41; age range: 25–65; average length of time on dialysis: NR	62% male; ethnicity NR	Single-site cross-sectional	Hospital Anxiety and Depression Scale, Multidimensional Health Locus of Control, Social Adjustment Scale, global rating of social support	K (15 levels prior to study) and IDWG (10 measures prior to study) approximately 3–6 months

Author, Year, Location	**Purpose**	**Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis**	**Sex (% male) and Ethnicity (% most prevalent ethnicity)**	**Methods**	**Predictor Measures**	**NA Measure**
Sherman et al. 1994, United States	To explore the deficiencies in delivered HD therapy due to missed and shortened treatments	*N* = 860; mean age: 53.6; age range: NR; average length of time on dialysis: NR	50.8% male; 53.7% Caucasian	Multi-site, longitudinal, descriptive	Demographics	Missed or shortened treatments
Somer & Tucker, 1992, unsure	To investigate racial difference in the relationship between spouse marital adjustment and dietary adherence	*N* = 68; mean age: 59 (patients), 61 (spouses); age range: 30–79 (patients), 34–79 (spouses)	72% male; 48% African Americans	Multi-site cross-sectional, descriptive with longitudinal component	Locke Marital questionnaire	IDWG and K (previous 3 months)
Steidl et al., 1980, Connecticut	To investigate the relationship between medical condition, adherence to treatment and patterns of family interaction	*N* = 23 (on PD); mean age: 43; age range: NR; average length of time on dialysis: 22 months	56% male; ethnicity NR	Single-site	Family structure among nine areas rated from video of family interaction, medical assessment evaluated by staff	Staff evaluated patients' adherence and assigned a composite score
Takaki & Yano, 2006, Japan	To assess differences between the relationships of self-efficacy and the internal health locus of control with compliance in HD patients	*N* = 397; mean age: 59.7 (men), 60.8 (women); age range: 21–89 (men), 29–88 (women); average length of time on dialysis: 99.0 months (men), 116.5 (women)	53% male; ethnicity NR	Multi-site cross-sectional, descriptive with longitudinal component study, survey, observational: theory: Bandura's theory of self-efficacy; transtheoretical model; theory of planned behavior	Self-efficacy of Health-Related Behavior Scale, Japanese version of the Health Locus of Control Scale	KT/V, BUN level, K level, IDWG

Takaki et al., 2003, Tokyo, Japan	To assess the possible variances of blood urea nitrogen, serum K and serum phosphorus levels and IDWG accounted for adherence of uremic patients on HD	*N* = 310; mean age: 59.2; age range: 21–88; average length of time on dialysis: 115 months	65.2% male; 100% Japanese	Multi-site, cross-sectional, descriptive with longitudinal component	Coping and self-efficacy scale	BUN, K, phos, IDWG
Taskapan et al., 2005, Turkey	To determine impact of psychiatric disorders on fluid restrictions, nutritional status and quality of life for HD patients	*N* = 40; mean age: 48.3; age range: NR; average length of time on dialysis: 28.4 months	62.5% male; 100% Turkish	Multi-site, cross-sectional, descriptive with longitudinal component, survey	Hamilton Depression Rating Scale, Hamilton Anxiety Rating Scale, Primary Care Evaluation of Mental Disorders, Mini-Mental State Examination, Short Form Health Survey 36	Medical records for IDWG, nutritional status
Testa & Plou, 2001, France	To investigate the clinical determinants of IDWG	*N* = 32; mean age: 71.3; age range: 25–88; average length of time on dialysis: 54.1 months	59% male; ethnicity NR	Single-site cross-sectional, descriptive with longitudinal component	Blood pressure and mean arterial pressure, dietary protein intake, calorie intake, sodium intake from calorie count, urea kinetic parameters calculated, defined those regularly high or normal on IDWG; sodium load was calculated, albumin, transferrin, C reactive protein	IDWG

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
Thomas et al., 2001, United States	To identify theory-based factors pertinent to adherence with diet	*N* = 276; mean age: NR; age range: NR; average length of time on dialysis: NR	46% male; 72.5% African American	Multi-site survey; theory: Bandura's social cognitive theory; health belief model; stages of change	Block Dietary Assessment Screening questionnaire, Knowledge questionnaire, Perceived Severity of Illness, attitudes toward adherence, environmental factors, perceived barriers, self-efficacy scale, perceived health beliefs/benefits	Diet: conformity in fulfilling the pertinent requirements of a prescribed diet on most occasions most days of the week
Tucker et al., 1991, Florida	To explore the relationship between nurses' attitudes toward patients and adherence	*N* = 29 patients; 8 nurses; mean age: 47 (patients), 34 (nurses); age range: 24–72 (patients), 30–39 (nurses); average length of time on dialysis: 48 months	NR	Single-site, cross-sectional, descriptive with longitudinal component	Nurses' attitudes	IDWG; K (averaged 3 months prior to study and 1 month during study)
Unruh et al., 2005, United States	To assess dialysis attendance and markers of dietary NA in HD patients	*N* = 1,041; mean age: >17 years; age range: NR; average length of time on dialysis: NR	53.70% male; 62.5% African American; 62.5% Caucasian; 5.3% other	Multi-site, cross-sectional, descriptive with longitudinal component, survey	Self-report questionnaire; Karnofsky Index for Functional Status, Index of Coexistent Disease, Health Experience Questionnaire	Lab values for albumin, creatinine, phos, K and hematocrit, as well as KT/V

Vives et al., 1999, Spain	To study the relationship between the level of adherence to treatment and diet and locus of control	*N* = 31; mean age: 63.32; age range: 40–82: average length of time on dialysis: 35.06 months	74% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component	Nottingham Health Profile, Multidimensional Health Locus of Control	K (>5.5 mmol/L), phos (>1.94 mmol/L), IDWG (>2.5 kg); drug treatment
Weed-Collins & Hogan, 1989, Ohio	To determine the extent to which knowledge and health beliefs relating to phosphate-binding medications predict adherence	*N* = NR; mean age: NR; age range: 25–80; average length of time on dialysis: NR	43% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component	Knowledge and health beliefs survey (by Cummings, 1982)	Average of three consecutive phos measured once per month; NA if >5.5 mg/dL
Wenerowicz et al., 1978, Wisconsin	To examine the impact of locus of control on adherence	*N* = 19; mean age: 36; age range: 19–70; average length of time on dialysis: 6.7 months	68% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component	Rotter Internal-External Locus of Control	Diet: K <5.5 mEq/L); medication (antacid ingestion): phos (>4.5 mg%); fluid and salt: IDWG (>2.6 kg); dietary protein: BUN (>100; 3 months prior to study)
Wiebe & Christensen, 1997, Iowa	To examine the ability of health beliefs and personality to predict adherence	*N* = 70; mean age: 55.95; age range: NR; average length of time on dialysis: 140.58 months	60% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component; theory: health belief model	Health Belief Model, conscientiousness for the NEO Five Factor Inventory	Fluid: IDWG (six before survey and six after); diet and medication: phos (mean of two closest to survey)

Author, Year, Location	Purpose	Sample Size, Mean Age, Age Range, Average Length of Time on Dialysis	Sex (% male) and Ethnicity (% most prevalent ethnicity)	Methods	Predictor Measures	NA Measure
Yanagida et al., 1981, United States	To examine the relationship between denial and fluid adherence	*N* = 46; mean age: 45; age range: 15–66; average length of time on dialysis: 36 months	52% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component	Marlow-Crowne Social Desirability Scale; Beck Depression Inventory, Nowicki-Strickland Internal-External Scale; Response to Illness questionnaire	Physiological data including weight, hematocrit, BUN, creatinine, calcium, phos, K, sodium, choloride, carbon dioxide (9 months prior to survey)
Zetin et al., 1981, California	To examine the relationship between locus of control and adherence	*N* = 15; mean age: 49.7; age range: 20–68 (males), 22–74 (females); average length of time on dialysis: 30.2 months	53% male; ethnicity NR	Single-site, cross-sectional, descriptive with longitudinal component	Rotter Internal-External Locus of Control, Zung Anxiety, Zung Depression, Beck Depression Inventory, Hamilton Anxiety and Hamilton Depression Scales	Diet: K <5.5 mEq/L); medication (antacid ingestion): phos (>4.5 mg%); fluid and salt: IDWG (>2.6 kg); dietary protein: BUN (>100; 3 months prior to study); global compliance score was calculated
Zrinyi et al., 2003, Location not reported but researchers are from Switzerland and Hungary and one inclusion criteria was to speak Hungarian	To determine how dietary self-efficacy is related to biochemical markers and self-report behavioral outcomes	*N* = 107; mean age: 57.6; average length of time on dialysis: NR	49.5% male; ethnicity NR	Multi-site cross-sectional, descriptive with longitudinal component; self-report; medical records; theory: Bandura's self-efficacy	Situational Dieting Self-Efficacy Scale; Patient reactions assessment (staff patient relations), Renal Adherence Attitude questionnaire (self-reported attitude to adherence)	Renal Adherence Behavior Questionnaire (self-reported diet/fluid restriction, K, phos self-care, sodium adherence)

Abbreviations: BUN, blood urea nitrogen; CAPD, continuous ambulatory peritoneal dialysis; HD, hemodialysis; K, potassium; PD, peritoneal dialysis; IDWG, interdialytic weight gain; med, medication; NA, non-adherence; NR, not reported; phos, phosphorus.

Mastering Hemodialysis to Reverse Patterns of Missed and Shortened Treatments

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Missed and shortened treatments have potentially grave health consequences for dialysis patients, placing them at higher risk for fluid overload and increased hospitalizations. Missed treatments further negatively impact dialysis center revenues. Mindful of the social worker's dual ethical responsibility to patients and employing agencies, the investigators proposed a research study aimed at reversing patterns of missed and shortened treatments. Drawing on the pioneering work of Prochaska and DiClemente, a transtheoretical model of behavioral change was adapted for nephrology social work with treatment-resistant dialysis patients in a comparative study involving three treatment approaches. The findings suggest improved motivation for treatment adherence, fewer hospitalizations and a decrease in missed and shortened treatments for patients in the social work intervention group.

INTRODUCTION

Missed and shortened treatments exact a heavy toll on the health status of hemodialysis (HD) patients, potentially contributing to higher rates of hospitalization or death (Leggat, 2005; Loghman-Adham, 2003; McKinley, 2000). Patients with end-stage renal disease (ESRD) are hospitalized more frequently than patients with other chronic diseases, and missed treatments account, in part, for excessive use of emergency room care by patients on HD (Mallappallil et al., 2005). Missing one or more treatments per month increases the patient's risk of death, with each missed treatment associated with a 10% increase in mortality (Bander & Walters, 1998). Missed treatments are also thought to be associated with poor understanding about one's condition (Johnstone et al., 2004), increased likelihood of fluid overload, lower functioning, decreased well-being and the desire to terminate treatment altogether (Mazzella, 2004). In contrast to other reports suggesting that missing dialysis altogether is a rare occurrence (e.g., Christensen & Ehlers, 2002), Bander and Walters (1998) report that missing treatments is a habit that usually forms in the first 6 months of a patient's treatment and remains stable over time. Nephrology social workers report anecdotally that this phenomenon is far from uncommon. There is a need to understand *why* patients on HD miss or shorten treatments and to intervene in a way that improves and prolongs patients' life quality.

Mallappallil and colleagues retrospectively reviewed a convenience sample of 181 out of 403 emergency room visits by HD patients at an urban teaching hospital. The key findings reveal that fewer than 5% of emergency room visits resulted in hospital admissions; 7% of the ESRD patients had missed their HD sessions; and treatment could have been easily administered in an outpatient setting. In other research by Sherman et al. (1994), a randomly selected sample of 860 patients with ESRD was assessed to determine the frequency of missed and shortened treatments. Fifty percent of patients either missed or shortened treatments (or both) over a 12-week period covering 28,108 treatments. Another study on the incremental cost of providing adequate HD reveals that males, African Americans in particular, are over-represented among patients receiving inadequate dialysis due to more frequent shortening of treatment time (Sehgal, 2003). A fourth study conducted by an international team of medical researchers (Bleyer et al., 1999) found that out of 415 U.S. patients, 147 missed 699 treatments over a 6-month period (calculated as 28.1 missed treatments per 100 patient-months or 2.3% of all prescribed treatments). This outcome compared with 0 missed treatments per 100 patient-months for patients from Japan and 0 missed treatments per 100 patient-months for patients from Sweden. This finding by Bleyer and his colleagues suggests that non-adherence is far more prevalent in U.S. patients undergoing HD than in Swedish and Japanese patients.

In other clinical research, Kutner et al. (2002) identify smoking as a significant marker of priority placed on health status among a cohort of HD and peritoneal dialysis patients in Atlanta, GA. Kutner et al. report that patients who skip or shorten treatments and patients with excessive serum phosphate values are more likely to be smokers. Their finding suggests that smoking

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may explain, in part, why patients miss or shorten their treatments. In this same research on the psychosocial predictors of non-adherence, patients who skipped treatments were younger (p = 0.00007), more likely to be African American (p = 0.02), and less likely to report a household income greater than $20,000 ($p$ = 0.003) than patients who had not skipped treatments (Kutner et al., 2002).

Others have suggested that physical discomfort, transportation problems, inconvenient therapeutic regimes (including dietary restrictions, medications and restricted fluid intake) as well as demographic variables (including age, marital status, educational level and socioeconomic status) can influence adherence (Loghman-Adham, 2003; McKinley, 2000). Despite the rich data concerning missed and shortened treatments, little is known about the *reasons* patients give for missing their treatments or shortening their time on the dialyzer. Although the renal care industry has identified psychosocial issues as important determinants of successful renal disease management in high-risk patients, more research needs to be done in a meaningful way (Johnstone, 2005; Neal et al., 2005) to engage patients who miss or shorten their treatments.

PURPOSE OF THE RESEARCH

The researchers aimed to reverse patterns of missed and shortened treatments at an outpatient dialysis center located in the Tampa Bay area of west central Florida where, in response to the social worker's internal continuous quality improvement questionnaire, patients reported that they missed or shortened treatments due to schedule conflicts with work and child care, hospitalizations, not feeling well or feeling well enough to skip saying "my labs were good." In response to patient feedback, the dialysis center administrators added a patient educational component that included chair-side video instruction on ESRD processes as well as didactic instruction provided by the nursing staff. The authors compared the effectiveness of these two educational modalities for reducing missed and shortened treatments with a social work intervention based on a cognitive-behavioral, psychoeducational approach. All three modalities assumed that more information about dialysis would correlate with greater adherence to treatment. Using the psychoeducational approach, the authors targeted the most treatment-resistant patients to address the psychosocial dynamics underlying missed and shortened treatments and actively engage patients in a change process through an instructional format delivered over four weekly sessions. The term *treatment-resistant* denotes patients with missed treatment patterns, who struggle with treatment adherence, and miss, on average, four or more treatments per month. The study builds on the researchers' previous findings that suggested the efficacy of a group cognitive-behavioral intervention for mediating depression and social support (Cabness et al., 2006).

STUDY DESIGN

The research intervention was a nonrandomized, quasi-experimental design targeting treatment-resistant patients for change following exposure to the social work group intervention over 4 weeks. A comparison group of patients receiving video instruction (group 1) and didactic teaching by nursing staff (group 2) was randomly selected by a nurse to reduce researcher bias. The authors sought to compare the effectiveness of the social work group cognitive-behavioral intervention (group 3) with the two other instructional modalities, as evidenced by sustained positive changes in patient behavior when measured at 30 days, 60 days, 90 days and 6 months following the interventions.

All patients were invited to attend a series of four classes, entitled "Mastering Hemodialysis." Flyers were posted in the dialysis center and invitations were extended to patients with a history of missing and shortening their treatments. The patients were encouraged to attend if they felt they were struggling with making changes in their health lifestyles. They were invited to attend classes and listen to new coping strategies with no pressure to make any changes in their treatment regime unless they chose to do so. The psychoeducational approach provided patients with information on the history of dialysis, with photographs of early dialyzers; education on the function of the kidneys and specific parts of the body that are affected when they fail; cognitive-behavioral techniques regarding thought processing, associated feelings and reframing; transplant information and the importance of adherence; setting goals and formulating action steps to achieve them; and finally some tips for addressing relapse. In each class, they also had opportunities to discuss what they had learned, how they felt and changes that they had successfully implemented or had not been able to make. Using motivational interviewing, the social worker acknowledged each patient's efforts in achieving personal goals. Miller and Rollnick (2002) define motivational interviewing as a client-centered counseling style for eliciting behavior change by helping clients explore and resolve ambivalence.

Patients were offered incentives, in the form of a gift card drawing, to attend each class. Wal-Mart gift cards were also given at pre- and post-testing following the administration of the SF-36v2, BDI–FastScreen and a patient questionnaire created by the social worker. Refreshments were provided during each class, and consultation was sought from the center's dietitian on acceptable types of snacks for the patients. Samples of all types of binders were available to the patients to encourage dietary adherence. Arrangements were made for patients who required transportation to attend the classes.

THEORETICAL FRAMEWORK

The research proposed to test a stage model of behavioral change, developed by Prochaska and DiClemente (1983), toward decreasing patient-identified risk factors for missed and shortened treatments. Prochaska and DiClemente identified six stages of behavioral change: precontemplation, contemplation, preparation, action, maintenance and relapse. Their cognitive-behavioral model has been further developed to embrace affective states as well, thereby adding the transtheoretical component. The transtheoretical model has been found useful for assessing the cognitive stage of patients in the process of changing specific health behaviors. The model has been used successfully for smoking cessation (DiClemente et al., 1991), improving dietary behavior (Campbell et al., 1994), increasing mammography rates among women at mid-life (Rakowski et al., 1998) and consenting to cadaveric organ donation (Robbins et al., 2001). It is believed that the research reported here is the first formalized study to apply the transtheoretical model of behavioral change (Velicer et al., 1998) to treatment-resistant HD patients.

SAMPLE CHARACTERISTICS

The social work intervention group consisted of 11 males and 3 females (*n* = 14). The majority were African American (76.92%), ranging in age from 25 to 66 years, with a mean age of 45.5 years. Nearly all had completed high school and most were unemployed. Four were smokers. The average length of time on dialysis was 1.14 years. The comparison group, mostly African Americans (79%), consisted of 7 males and 7 females (*n* = 14), ranging in age from 22 to 59 years, with a mean age of 44.6 years. There were no smokers in this group. The average length of time on dialysis was 1.36 years. All patient annual income was <$20,000. The major difference between the two groups resided in the rate of treatment adherence. The sample characteristics for all participants are shown in Table 1.

Table 1

Sample Characteristics (*n* = 28)

Gender	***n***	**Mean Age**
Male	18	50.39
Female	10	36.40
Ethnicity		
African American	23	43.52
Caucasian	3	54.00
Hispanic	2	54.00
Length of Time on Dialysis		
1–6 months	4	48.75
7–12 months	4	47.75
More than 1 year	6	39.00
More than 2 years	14	46.50
Education		
Less than 12 years	8	35.50
Graduated high school	9	47.67
Some college	6	45.00
College graduate	5	57.60
Marital Status		
Single	14	39.29
Married	6	45.33
Separated	3	54.33
Divorced	3	56.33
Widowed	2	58.50

KEY FINDINGS

For the 3 months prior to the social work intervention, patients who were enrolled in the intervention group had the highest number of missed and shortened treatments as well as the highest rate of inpatient admissions. Following the interventions, a review of the aggregate mean group differences revealed positive changes in the number of missed treatments, shortened treatments and inpatient admissions for all three groups, with the greatest change occurring in the social work intervention group. The changes were evaluated at 30, 60 and 90 days after the intervention and compared with pre-intervention adherence rates. However, there was also evidence of sustained positive changes in each category for the social work intervention group when measured at

6 months following the intervention. Missed treatments at 3 months positively and significantly correlated with missed treatments at 6 months ($r = .867$, $p \leq 0.01$) for the social work intervention group, suggesting that fewer missed treatments at 90 days were also likely, under the same conditions, at 180 days. The findings are both statistically significant and clinically important. These changes are shown in Tables 2–4.

Table 2

Comparison of Group Mean Differences for Missed Treatments

Group	PRE	MIST x 3	Difference Between Means	MIST x 6	Difference Between Means	*N*
Video	1.00	0.86	-0.14			7
RN teaching	1.57	0.57	-1.00			7
SW group	6.46	2.15	-0.77	3.46	-3.00	14

Differences between the means in missed treatments are shown before the interventions (PRE) and at 3 months post-intervention (MIST × 3) for all three groups, and at 6 months post-intervention (MIST × 6) for the group receiving the social work intervention only.

Table 3

Comparison of Group Mean Differences for Shortened Treatments

Group	PRE	SHORT x 3	Difference Between Means	SHORT x 6	Difference Between Means	*N*
Video	4.17	3.00	–1.17			7
RN teaching	1.71	1.14	–0.57			7
SW group	2.46	2.15	–0.31	2.15	–0.31	14

Differences between the means in shortened treatments are shown before the interventions (PRE) and at 3 months (SHORT × 3) post-intervention for all three groups, and at 6 months post-intervention (SHORT × 6) for the group receiving the social work intervention only.

Table 4

Comparison of Group Mean Differences for Inpatient Admissions

Group	PRE	INP x 3	Difference Between Means	INP x 6	Difference Between Means	*N*
Video	0.00	0.29	0.29			7
RN teaching	1.43	0.43	–1.00			7
SW group	1.46	0.85	–0.61	0.38	–1.08	14

Differences between the means in inpatient admissions before the interventions (PRE) and at 3 months (INP × 3) for all three groups, and at 6 months post-intervention (INP × 6) for the group receiving the social work intervention only.

Unlike Kutner et al. (2002), the authors found no association between smoking and shortened treatments or between smoking and excessive serum phosphate levels, perhaps owing to the small sample size and so few smokers among any of the groups. However, the authors observed that the women in the intervention group tended to miss treatments at a higher rate than the men, leading to a gender effect. This supports the finding that demographic variables influence adherence (Loghman-Adham, 2003; Takaki et al., 2007). The authors further noted the overall improved functioning of the social work intervention group, as evidenced by the marked differences between pre- and post-test scores of group 3 on the SF-36v2 when compared with the baseline comparison group scores (post-intervention only) following the administration of the video and didactic modalities. The SF-36v2 scores are shown in Table 5. Similarly, differences in the BDI–FastScreen pre- and post-test scores of the social work intervention group were noted and compared with the baseline comparison group scores. These figures are shown in Table 6.

CONCLUSION

Consistent with Johnstone et al.'s (2004) findings, our research data suggest that missed and shortened treatments are likely to be associated with poor understanding about one's condition and the dialysis process. In the current study, the greatest improvements were made by patients attending all four of the "Mastering Hemodialysis" classes. The educational materials were presented objectively and group discussion was encouraged. Consistent with motivational interviewing techniques, patients were not pressured to change and there were no overt expressions of expectations or recommended outcomes. The research demonstrates further

Table 5

SF-36v2 Transformed Scores (0-100 Scoring)

	Intervention Group		Comparison Group *(baseline)*
	Pre-test	**Post-test**	**Post-test only**
Mean			
Physical functioning (PF)	54.48	↑58.22	56.43
Physical role (RP)	45.42	↑62.50	50.00
Body pain (BP)	63.27	↑64.43	61.00
General health (GH)	43.38	↑49.50	52.71
Vitality (VT)	51.25	↑63.69	58.48
Social functioning (SF)	63.33	↑77.68	66.35
Emotional role (RE)	67.22	↑80.36	61.01
Mental health (MH)	70.67	↑78.13	69.55

Note: SF-36v2 scores were tabulated using QualityMetric™ scoring software

Table 6

Comparison of Group Mean Scores on the BDI—Fast Screen

Group	Pre-BDI	Post-BDI	Difference	*N*
Video		1.2857		7
RN Teaching		3.2857		7
SW Group	1.3571	0.7692	–0.59	14

Comparisons of the mean scores on the BDI–FastScreen for all three groups (post-intervention only) and the difference between the means (pre- and post-intervention) for the group receiving the social work intervention.

that reversing patterns of missed and shortened treatments is likely to occur when patients are guided, following a transtheoretical model of change, to assimilate their own conclusions about their behaviors based on the information available to them and then begin to integrate this knowledge with their own personal improvement goals.

The gender effect associated with missed treatments is thought to be related to women's ownership of family issues (e.g., child care during summer and holiday periods, sick children, housing and transportation) at a higher rate than men in the study. More research is needed to assess the influence of seasonal variations in women's treatment adherence.

The study is limited by the small sample size and non-random, single-subject design, which makes statistical analysis difficult to achieve despite clinical observations pointing to the overall effectiveness of the social work intervention. Adding pre-intervention baseline scores for the comparison group would yield a "cleaner" research study design. The research reported here is described by Kerlinger (1992) as a "one-shot-case study." Although we have concluded that the social work intervention was effective, "with such a design the conclusion is weak" (Kerlinger, 1992). The authors cannot think of a greater reason to encourage more research on the efficacy of renal social work interventions. Clearly, the risk of oversampling increases with each research intervention with single subjects. Ideally, nephrology social work research with dialysis patients should engage multiple sites for attaining larger samples. Such an approach would permit random assignment to different treatment groups and provide data that have greater likelihood of approaching statistical significance.

Staff involvement is very important to patient morale. The authors believe that fostering a patient-centered environment in dialysis centers might further contribute to decreases in the number of missed and shortened treatments. A patient-centered orientation assures alternatives, such as rescheduling treatment days or times, when patients cannot keep their treatments. Of course, patients should be encouraged to attend their scheduled appointments but, when emergencies occur, they should be counseled by members of the treatment team to reschedule, so as not to shorten treatments or miss altogether.

The authors suggest providing classes to new patients, using the "Mastering Hemodialysis" materials (available from the authors), to deter patients from developing the patterns of missed and shortened treatments that frequently develop during the initial months of dialysis. They further recommend increased advocacy with transportation agencies on a macrosystems level to ensure that patients have the means to become and remain treatment adherent.

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Volunteering Improves Adherence to Dietary Regimens and Outlook of People With Chronic Kidney Disease

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The research reported here builds on a corpus of studies that have found strong positive effects of volunteering on depression, self-esteem and adherence to medical regimens. Patients with chronic kidney disease at a community hemodialysis facility volunteered to act as participants in a control condition or an experimental (volunteer) condition that involved 1 hour/week volunteer service. The patients were matched with a volunteer activity from possibilities identified by the hemodialysis unit social worker and showed reliable increases in adherence as measured by control of fluid weight gain and potassium levels. In addition, qualitative analysis of pre- and post-experiment interviews with participants correlated well with measures of depression and self-esteem. Depression indicators declined for those in the volunteer condition but not for those in the control condition. Our discussion includes strong recommendations that volunteer opportunities developed and facilitated by the unit social worker for patients on dialysis are an investment of resources that produce a significant payoff in patient physical and psychological health.

INTRODUCTION

People who work daily with patients who have chronic kidney disease (CKD) observe common factors that have a negative impact on this large group of people. Social workers describe the continuing adjustment issues that are often reflected in patient needs, such as the need for self-esteem enhancement and help in alleviating depression (Cvengros et al., 2005; Kimmel, 2005; Kimmel & Peterson, 2005). Depression, for example, affects many with CKD; a recent study (n = 207), estimated the prevalence of depression among patients with CKD to be nearly 20% (Cvengros et al., 2005), while Piraino et al. (2003) reported the incidence of depression to be as high as 25% for CKD patients beginning dialysis in a review of the literature. However, while all agree that depression is a major problem in this population, estimates can range from 5 to 50% depending on the instrument used to diagnose depression (Kimmel & Peterson, 2005). In addition to the need for addressing psychological factors is the need for the staff to address issues affecting physical health, such as patients' adherence to dietary restrictions (Bannister & Snelling, 2006). Dialysis patients have many co-morbid conditions (e.g., cardiovascular complications, infections, anemia, hypertension) and, collectively, are immunocompromised (Fehr et al., 2004). Thus, the importance of health maintenance and patient adherence to prescribed dialysis regimen while undergoing dialysis cannot be minimized.

Vocational rehabilitation (VR), among other interventions, has provided a route for addressing some of these issues (Curtin et al., 2003). For these patients, psychological health still includes the need to feel as independent as possible and to be contributing members of society (Cvengros et al., 2005). VR is one way of achieving these independence and productivity goals. However, for various reasons, a number of patients are unable to participate in VR activities (Curtin et al., 2003; Dinwiddie, 2004). The goal of VR is gainful employment. Because of their illness, many CKD patients have a difficult time participating in traditional jobs. Other factors reduce the time available for VR and pursuance of job responsibilities, such as time spent on dialysis, sick days due to CKD and related health issues and numerous medical appointments. Finally, pragmatic issues such as accessibility to VR (e.g., travel from rural areas) and ability to drive (e.g., for home-bound patients) make VR logistically inconvenient.

Volunteerism has been shown to have an impact on health and affect in other medical conditions (Harris &

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Thoresen, 2005; Musick & Wilson, 2002) and has been overlooked in CKD. Anecdotal evidence and more formalized examinations of volunteerism's benefits (e.g., Oman & Thoresen, 2000) indicate that people feel better, function better and are more compliant with medical regimens when they feel that they have a purpose in life and are having a positive impact on others around them (e.g., Morrow-Howell et al., 2003). However, volunteerism has not been specifically related to dialysis patients and their particular needs. The present research pursues the benefits of volunteerism to the enhanced health and positive outlook of dialysis patients.

RESEARCH BACKGROUND

Research has documented the relationship between volunteerism and perceptions of well-being. Morrow-Howell and colleagues (2003) found that 8 of 10 volunteers reported experiencing an increase in well-being, having more friends and acquaintances and making more productive use of their time. Reports of other positive effects of volunteerism are that it "provides a sense of control over one's life and one's environment, thus alleviating depression," (Mirowsky & Ross, 1989) and that volunteerism increases "perceived self-efficacy, self-esteem, and positive affect" (Musick & Wilson, 2003).

Volunteering has been reported to be particularly beneficial for the elderly population (usually defined as over 60 years of age) because it can protect them from "the hazards of retirement, physical decline, and inactivity" (Fischer & Schaffer, 1993). Wheeler et al. (1998) reported in their meta-analysis of research examining the effects of volunteering on the elderly that, despite differences in socioeconomic status and physical health, there was a strong positive relationship between volunteering and life satisfaction. Aside from the fact that a large number of dialysis patients are in this age group, it seems that even many younger patients share some characteristics typically associated with the older group (Kimmel & Peterson, 2005). These include loss of employment and the self-esteem that comes from doing productive work, reduced participation in outside activities and increased loneliness, a preoccupation with health, the loss of ability to perform some previously mastered functions, a perceived loss of control over life and elevated levels of depression (see Kimmel & Peterson, 2005 for review).

Volunteerism, extensively studied in elderly populations, has produced opportunities for benefits that counteract or ameliorate some of these consequences. Based on a theory proposed by Lin et al. (1999), psychological and social resources are mechanisms that can explain the relationship between volunteerism and health. A number of studies have examined processes related to these mechanisms and found (a) increases in self-assurance and confidence (Midlarsky, 1991); (b) increases in self-esteem and consequent well-being and decreases in depression (Wuthnow, 1991); and (c) reduction in loneliness and enhanced feelings of self-worth (Omoto et al., 1993). In each of these instances, and among others, volunteerism is the mediating link between improved involvement with psychosocial resources providing information and support and positive social interactions that counter the withdrawal seen in the elderly and those affected by chronic disease (Musick & Wilson, 2003).

PRESENT RESEARCH

The purpose of the present research was to examine the experience of volunteerism for individuals with CKD undergoing hemodialysis. There were four specific research questions of interest:

1. Is there a relationship between volunteering and self-esteem?
2. Is there a relationship between volunteering and depression?
3. Is there a relationship between volunteering and adherence to a treatment regimen?
4. How does the experience of volunteering impact individuals on hemodialysis?

Specifically, the present study examined the positive effects of volunteerism in a self-selected sample of patients undergoing hemodialysis. Patients were matched with volunteer opportunities and monitored for adherence to dietary regimens and changes in depression and self-esteem. In addition to the evaluation of these quantitative variables, observations and interviews provided correlational evidence of the positive effects of volunteerism.

In summary, the present research hypothesized that the effect of volunteer activity would result in mood enhancement, an increase in feelings of self-worth and a concurrent increase in adherence to dietary restrictions.

METHODS

Participants

There were 15 individuals with CKD undergoing hemodialysis at a community hemodialysis center who volunteered to participate in the study. The total population undergoing dialysis at the center during the time of the study was 40 patients. The participants' ages ranged from 26 to 85 years with a median age of 57 years, and there were 8 women and 7 men. Two of the participants had more than a high school education, and two participants had not completed high school. Of the sample, seven participants were married; the remaining participants were either single (*n* = 4), divorced (*n* = 2) or widowed (*n* = 2). The participants in this sample lived in a rural, Midwestern community. Participants were randomly assigned to an experimental condition (*n* = 8) in which they were given volunteer assignments (*volunteer*) or assigned to a *control* condition (*n* = 7) in which they were not given volunteer assignments. Five of the participants in the experimental condition were on state-assisted Medicaid; however, all of these individuals became Medicaid eligible after beginning dialysis as the result of the many expenses associated with dialysis. Two of the participants in the control condition were on Medicaid; both became eligible after beginning dialysis. None of the participants were employed. The length of time that the participants had undergone hemodialysis ranged from less than 5 months to 14 years, as recorded at the onset of the study. Participation in the study was approved by each person's physician. All participants engaged in every aspect of the study and were given $15 department store gift cards at the beginning and end of the study to reimburse them for gas money and interview time.

Materials

Materials included the Center for Epidemiologic Studies Short Depression Scale (CES-D 10), the Rosenberg Self-Esteem Scale (SES) and an interview questionnaire developed by the investigators.

The CES-D10 is a 10-item version of the 20-item CES-D, and is available at no charge from the Stanford Patient Education Research Center. It serves as a self-report depression instrument with instructions for the respondent to indicate the frequency with which the feeling expressed in each item was experienced according to the stem, "During the past week …" The CES-D 10 requests responses on a Likert-type scale, with 0 indicating *rarely or none of the time (less than 1 day)*, 1 indicating *some or a little of the time (1–2 days)*, 2 indicating *occasionally or a moderate amount of time (3–4 days)*, and 3 indicating *all of the time (5–7 days)*. An example of one of these items is, "I was bothered by things that usually don't bother me." Two of the items (nos. 5 and 8) are reverse-scored. The score on the CES-D 10 is the sum of the 10-item weights, with a score of 10 or greater indicating depression. Internal consistency (reliability) for the CES-D 10 is reasonably high at 0.84. In a test of the scale with 605 subjects with chronic disease (Lorig et al., 2001; Andreson et al., 1994), the observed range was 1–30, with a mean of 12.9 (SD = 6.13).

The SES is one of the most widely used self-esteem measures in social science research (Greenberger et al., 2003). It is a self-report Likert-type instrument with 10 items answered on a 4-point scale ranging from *strongly agree* to *strongly disagree*. In the present study, for scoring five of the items, the labels were weighted such that *strongly agree* was assigned a value of 3, while *strongly disagree* was assigned a value of 0. An example of one of these items is, "I feel that I have a number of good qualities." The remaining five items are reverse-scored. An example of one of these items is, "I certainly feel useless at times." Thus, in this administration, the total score on the SES was the sum of the two sets of items, and could range from 0–30, with 30 indicating the highest score possible. Greater self-esteem is indicated by a higher score. Developers of the scale (see Blascovich & Tomaka, 1993; Rosenberg, 1986) report that it has high reliability, with test–retest correlations typically in a range of 0.82 to 0.88, and Cronbach's alpha ranging from 0.77 to 0.88 for a number of studies.

The interview questionnaire included six questions designed to encourage participants' self-disclosure of their general moods, feelings about themselves and attitudes about their medical conditions and hemodialysis treatments. The complete questionnaire can be seen in Appendix A.

Procedure

Five volunteer activities were selected from a list identified by the social worker at the hemodialysis unit who made contact with a supervisor or coordinator at each of the volunteer sites. Sites included a food pantry in need of help stocking shelves, helping customers, cleaning, etc.; a literacy council in need of volunteers to read and audiotape books for clients; nursing homes in need of volunteers to write letters and/or visit shut-ins and mend clothes for the sick and elderly; and a hemodialysis unit renal dietician in need of a volunteer to clip coupons for patients. (See Appendix B for additional volunteer activities identified by the social worker.) Each volunteer was matched with an activity according to his or her health, mobility and interest. The volunteers committed to 1 hour of volunteer activity per week. Volunteers were given the option of being matched with a second volunteer activity if the first activity did not work out. One volunteer availed herself of this option.

Just prior to the onset of and at the conclusion of the 3 months specified for the volunteer activities for those in the experimental condition, participants in each condition gave informed consent; demographic information including age, gender, educational level, relationship status with significant other and length of time on dialysis; and responses to the SES and the CES-D 10. Completion of the instruments was self-paced and required an average of 5 minutes each for the SES and the CES-D 10. Additionally, the interview questionnaire was administered to each participant in each condition at the onset and conclusion of the study. Interviews were conducted by a hired research assistant and tape-recorded for later transcription. On average, interviews took approximately 1 hour to complete. The research assistant was not previously known to the participants.

Adherence to treatment regimen was evaluated on the basis of two primary factors. First, adherence to prescribed dialysis diet was indicated by (a) phosphorous levels (adherence was represented by a monthly reading of less than 6 mg/dL); and (b) potassium (K) levels (adherence was represented by a monthly reading of less than 6 mEq/L as recommended by the National Kidney Foundation Kidney Disease Outcomes Quality Initiative guidelines). Second, adherence to prescribed fluid allotment was evaluated by the amount of fluid weight gain between dialysis treatments. Adherence was represented by a weight gain of less than fluid allotment. Fluid allotment was established as 3% of the patient's base (dry) weight or adjusted base weight for obese patients. Fluid weight gain was measured in kilograms on a calibrated standard scale at the dialysis center.

The hemodialysis unit dietitian recorded K and phosphorus (PO_4) levels for each participant once per month, beginning 2 months prior to the onset and ending 2 months following the end of the volunteer period. The dialysis staff recorded fluid weight gain (in kilograms) three times per week, at each hemodialysis appointment.

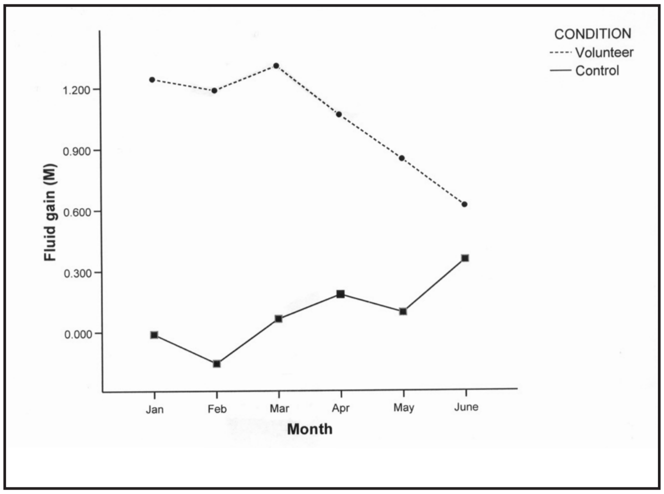
RESULTS

The data from one participant from the experimental condition who experienced a decline in health precluding his ability to act as a volunteer were not included in any part of the analyses. Thus, there were seven participants in the volunteer condition and six in the control condition who supplied complete data for the quantitative measures. Two patients were unable to complete the final interview; one participant from the control group received a kidney transplant, and one participant from the volunteer group died before the post-experiment interviews were conducted. Examination of the findings from the quantitative measures revealed that they were consistent with the qualitative data from the interviews and suggests the reliability and validity of those measures for this sample. Of most importance for the quantitative analyses were those measures indicating adherence to dietary restrictions: fluid weight gain and K and phosphorus levels.

Fluid Weight Gain

Figure 1 shows the mean fluid weight gain (loss) for volunteer and control conditions for each of the months prior to (January, February), following (June) and comprising (March–May) the experimental time period. As can be seen, overall fluid weight gain appears greater for those in the volunteer condition than for those in the control condition. Because a random assignment procedure was used, this outcome could not have been predicted and was consistent throughout the course of the experimental time frame. However, once the volunteer period began, amount of fluid weight gain appears to steadily decline for those in the volunteer condition while, concurrently, it appears to increase somewhat for those in the control condition. A 2 (condition) × 6 (months of the experiment) mixed (between subject × within subject) ANOVA confirmed these observations. There was a statistically significant interaction between condition and the time course of the experiment, F (5, 60) = 3.701, $p < 0.01$, $MSE = 0.160$. The effect was strong as indicated by an eta^2 of 0.236. Likewise, there was a main effect of condition, F (1, 12) = 9.939, $p < 0.05$, $MSE = 2.146$, $eta^2 = 0.427$. However, there was no main effect of time course of the experiment, F (5, 60) < 1.0.

Figure 1. Mean fluid gain prior to, during and following the study



Simple main effects analyses of the months March through June for the volunteer condition showed that the reduction in fluid weight gain was reliable for those in the volunteer condition, F (3, 18) = 4.233, p = 0.02, MSE = 0.144. The effect was strong as indicated by an eta^2 of 0.414. Paired samples t-tests were used to evaluate change between months and revealed that the greatest reduction in fluid weight gain took place from the beginning months to the end of the volunteer period (March–June and April–June), $t(6)$ = 3.789 and 2.743, respectively, $p<.05$, while the change from month to month (March–April, April–May and May–June) was not statistically significant, $t(6)$ = 0.835, 1.618, and 1.944, respectively, $p >.05$.

In contrast, for those participants in the control condition, the increase in fluid weight gain (see Figure 1) was not statistically reliable, F (3, 18) = 1.215, MSE = 0.097, $p>0.05$. Follow-up paired samples t-tests comparing the increase between months supported this conclusion; the one increase in fluid weight gain that approached significance was that between May and June, $t(6) = -2.133$, $p = 0.077$; all other resulting increases in fluid weight gain were not statistically significant, $t \leq -1.298$, $p \geq 0.242$, in each case.

Simple interaction comparisons looked specifically for major differences in fluid weight gain between the volunteer and control conditions for those months in which the greatest changes appeared to take place—as participants had had sufficient experience with volunteering and following, April to May and May to June. As can be seen in Figure 1, the greatest difference between conditions was in fluid weight gain changes for each between May and June, at the conclusion of the volunteer period for this research. It was at this time that fluid weight gain was greatest for those in the control group while fluid weight gain was lowest for those in the volunteer condition, F (1, 12) = 8.318, p = 0.014, MSE = 0.050. The interaction was strong, as indexed by eta^2 at 0.409. In contrast, although there were different changes in fluid weight gain between those in the control and volunteer conditions, there was no reliable interaction between change and condition for the period April to May, F (1, 12) = 1.134, p = 0.308, MSE = 0.202.

K Levels

Initially showing higher levels of K than those in the control condition, the participants in the volunteer condition showed progressively lower levels of K over the course of the volunteer period. As can be seen in Table 1, all seven participants in the volunteer condition showed improvement in their K levels; this was indicated by a decline in levels to the acceptable range of 3.5 to 6.0 mEq/L from the first to the last month of the experimental time period. In contrast, only two participants in the control condition showed improvement in K levels as demonstrated by a decline to the acceptable range, while most (four participants) actually showed an increase in K levels above the acceptable range. These differences in response for the volunteer and control conditions were reliable, χ^2 (2) = 7.778, p <0.05.

Table 1. Percent Change in Potassium Level as a Function of Experimental Condition

Change in Potassium Level (% of condition)

Condition	Improved	Same	Worse
Volunteer	100	0	0
Control	29	14	57

Phosphorus Levels

As can be seen in Table 2, results were mixed for improvement in maintaining appropriate phosphorus levels for those in the experimental condition. Improvement in adherence as indicated by maintaining phosphorus levels in an acceptable range of 3.5 to 5.5 mg/dL was attained by three of the patients and three showed an increase beyond the acceptable range. On the other hand, six of the patients in the control condition showed an increase beyond the acceptable range. However, these differences between conditions were not statistically significant, χ^2 (2) = 3.00, p > 0.05. In contrast to the thrice-weekly measures of fluid weight gain, measures of K and phosphorus were made on a monthly basis. It should be noted that a small sample size with few repeated measures of a variable can result in more error variability that contributes to the statistical test and less power in the data for detecting real effects.

Table 2. Percent Change in Phosphorus Level as a Function of Experimental Condition

Change in Phosphorus Level (% of condition)

Condition	Improved	Same	Worse
Volunteer	43	14	43
Control	14	0	86

Depression and Self-Esteem

Of additional interest for the quantitative analysis were differences in response to pre- and post-experiment measures of depression and self-esteem. Scores on depression decreased overall from the first to the second administration of the CES-D 10 for participants in both the volunteer and control conditions. While the decrease in depression appeared to be greater for those in the volunteer condition (*M* = 9.57 versus 7.43, SD = 2.37 and 4.79, for the first and second CES-D 10 administration) than for those in the control condition (*M* = 8.83 versus 7.67, SD = 5.71 and 6.02, first and second administration), there was no interaction, *F* (1, 11) <1.0, *MSE* = 18.17, nor was the difference between conditions reliable, *F* (1, 11) <1.0, *MSE* = 28.70. Finally, the apparent overall reduction in depression was not reliable, *F* (1, 11) <1.0, p >0.05, *MSE* = 18.17.

There was no reliable change in self-esteem for either of the two conditions, as assessed by the SES. Examination of the mean pre-experiment SES scores for participants in the volunteer and control conditions showed little difference between the two; the mean SES scores for the volunteer and control conditions, respectively, were 20.50 (SD = 4.76) and 20.83 (SD = 4.26). The changes to mean SES scores of 19.67 (SD = 3.20) and 19.83 (SD = 5.85) for those in the volunteer and control conditions, respectively, on the post-experiment administration were not significant. Neither was there an interaction between time of administration of the SES and condition, nor were there main effects of change in SES scores or condition, *F* (1, 11) <1.0, for each effect. Note that self-esteem, according to one definition (Bem, 1967) is considered by many (e.g., Watson et al., 2002) to be a relatively stable personality characteristic and, as such, rapid change may not be observed easily by scales such as the SES. On the other hand, the definition of self-esteem as used in the present research—pride in self, self-respect, and self-worth (based on Bandura, 1997)—may be more sensitive to subtle changes that are better detected in the longer interview process (analysis to follow).

In general, although the examination of scores for the pre- and post-experiment administrations of the SES and CES-D 10 indicate no reliable changes related to the volunteer experience, the numbers in each condition were small and probably did not produce adequate power to detect an effect. In addition, there were only two administrations of these instruments—immediately before and at the end of the experimental period (6 months later). However, a trend toward a reduction in depression was indicated. This, considered along with the data from the pre- and post-experiment interviews of participants in this study, provides evidence for a role of volunteerism in achieving psychological improvement for patients in dialysis.

Qualitative Analysis of Interviews

The qualitative analysis focused primarily on the transcripts of semi-structured interviews conducted pre- and post-experiment. The analysis was conducted by two evaluators, independent of each other, and examined changes for each participant in the experimental and control conditions. However, indicators of change were also identified in informal observations of participants throughout the project by dialysis staff, revelations from participants' families and by participant verbalizations outside the interviews. In addition, observations were also recorded by the research assistant who called each participant twice throughout the project. In both pre- and post-experiment interviews, six questions were asked (see Appendix A).

Changes between pre- and post-experiment interviews were categorized using the following criteria:

1. Mood—for example, affect, more positively worded phrases, energy level and body language as observed by interviewer
2. Self-esteem—for purposes of this project, self-esteem is defined as pride in self, self-respect, and self-worth (Bandura, 1997; dictionary.com, n.d.)
3. Relationships—participant's relationships with people significant in his/her life
4. Sense of control—participant's sense of control over own life; sense of control regarding the adherence to dialysis regimen
5. Attitude toward dialysis—how positively or negatively a participant views his/her dialysis treatment and the necessity to integrate it into his/her life
6. Ability to make a difference—sense of generativity, self-efficacy or sense of capability (see Bandura, 1997)

Each of these six criteria were used by the evaluators to give a rating of change of *decreased or declined*, *stayed the same*, or *increased or improved*. What follows are summaries for each criterion across patients, including examples of statements indicating change. The examples given are not exhaustive. Participants in the study were given codes to facilitate reference to their comments and behavior; those in the experimental condition were coded with letters A, B, F, G, H and I and those in the control condition were coded with letters C, D, E, J, K and L. The examples that best illustrate the criteria came from all six participants in the experimental condition. However, only participants C, D and E, in the control condition provided comment or examples illustrating the criteria for their condition.

Mood criteria

Both evaluators found that all six participants in the experimental condition improved. The research assistant who conducted the interviews reported more positive body language and more desire to talk in the post-experiment interviews in participants in the experimental condition. Of those in this condition, she noted greatly improved eye contact for participant A, who also commented that "I can do a lot more that I used to" in the post-experiment interview as contrasted with "I wish I could do more" in the pre-experiment interview. Participant B expressed pride that, for the first time in years, she had the energy to weed her garden.

Of those participants in the control condition, both evaluators agreed that, according to the criteria, three participants declined in mood, two stayed the same and one improved. Participant C's improvement was indicated by changes such as her saying, "There are lots of things I can't do anymore" in the pre-experiment interview to talking about going out of her house more often in the post-experiment interview. Of the three participants who were noted to decline in mood, participant D stated, for example, "My moods are not too bad" in the pre-experiment interview as contrasted with, "I'm depressed. I get down and blue and depressed more than before" in the post-experiment interview. Both evaluators noted that participant E seemed less enthusiastic and more blasé toward life in the post-experiment than in the pre-experiment interview. The tone of his voice was not as animated in the post-experiment interview. Further, participant E stated, "Things are going beautifully" in the pre-experiment interview as compared with, "Things are going good" in the post-experiment interview.

Self-esteem criteria

One evaluator found that all six participants in the experimental condition improved. The second evaluator found that five participants improved and one stayed the same. In the post-experiment interview, participant F said, "Reading books on tape [the volunteer assignment] makes me feel smart." In the post-experiment interview, participant G said in a strong voice interpreted by the interviewer as reflecting pride, that "I stock a whole shelf in an hour. They seem to like me quite well." Previously, this participant was noted as showing hesitancy about even volunteering in a placement away from home. The research assistant noted during the interviews that participant H displayed a more self-assured body posture (e.g., sitting up straighter, shoulders not drooping) in the post-experiment interview as compared to that observed in the pre-experiment interview.

Of those participants in the control condition, both evaluators rated one participant as having declined, four as having stayed the same and one as having improved. Participant C, who both evaluators rated as improved in self-esteem said, "I have been getting out more and doing more things" in the post-experiment interview. However, in this case, an explanation for this improvement is offered by her concerns expressed in the pre-experiment interview about a particular relative; on the basis of her comments at the time of the post-experiment interview, this concern had been resolved.

Relationship criteria

Both evaluators rated one participant in the experimental condition as having stayed the same and five as having improved their relationships. Participant G said, "I get along reasonably well with my wife" in the pre-experiment interview as contrasted with saying, "I get along real well with my wife" in the post-experiment interview. Participant I stated having good relationships with children both in the pre- and the post-experiment interviews.

Of those participants in the control condition, both evaluators noted one participant as having declined in the quality of relationships, four as having stayed the same and one as having improved. Participant D, for example, noted by both evaluators as having declined, said, "I enjoy my relative because I ain't by myself anymore" in the pre-experiment interview as contrasted with, "I wish I could live by myself" in the post-experiment interview.

Sense of control criteria

Of those in the experimental condition, both evaluators rated one participant as having stayed the same and five as having improved; however, a different participant was rated by each evaluator as having stayed the same. Both evaluators agreed on the improvement of participant A, who said in the pre-experiment interview, "I have a little trouble with phosphorous." In the post-experiment interview, this participant said, "I'm doing better with phosphorous. I can control my diet." In the pre-experiment interview, participant G said, "Fluid is a big problem" as contrasted with the post-experiment interview in which he said, "I limit myself to so much fluid per day."

Of those participants in the control condition, both evaluators rated two participants as having decreased, three as having stayed the same and one as having an increase in sense of control. In the pre-experiment interview, participant E did not disclose any specific problems following the dialysis regimen, whereas in the post-experiment interview, he said, "I forget to take my pills every once in awhile."

Attitude toward dialysis criteria

One evaluator categorized all participants in the experimental condition as having improved in their attitude towards dialysis. The second evaluator rated two participants as having stayed the same and four as having improved. Participant F was noted by both evaluators as having improved. When asked about dialysis in the pre-experiment interview, she said, "God is mad at me for something" as contrasted with the post-experiment interview when she said, "God is giving me a second chance." Participant A, who was rated by both evaluators as having improved in her attitude toward dialysis, said in her pre-experiment interview, "I have a fear of how my disease will progress" as contrasted with the post-experiment interview when she said, "My health is pretty good." In the pre-experiment interview when asked about his dialysis treatments, participant G talked about problems with fluid weight gain and feeling "achy and just plain tired all the time." In the post-experiment interview, participant G said, "Dialysis is going real good. They're giving me good dialysis."

Of those participants in the control condition, one evaluator rated two participants as having declined in attitude toward dialysis, three as having stayed the same and one as having improved. The other evaluator rated three participants as having declined, two as having stayed the same and one as having improved. Participant C, who both evaluators found to be improved, said in her pre-experiment interview, "Dialysis is a big stumbling block." In her post-experiment interview, she said, "I don't like it, but I can accept it." Participant E, rated as having declined by both evaluators, said in the pre-experiment interview, "I like having a health care person" as compared with his statement in the post-experiment interview, "It is hard having a health care person come to my home every morning." This same participant said in his post-experiment interview, "It is hard coming to dialysis three times a week," whereas there were no negative comments about dialysis in the pre-experiment interview. In the pre-experiment interview, when asked about how he felt about dialysis, participant D said, "I have come to live with it. It doesn't get me down anymore." In the post-experiment interview, this participant said his medical condition "worries me."

Ability to make a difference criteria

Both evaluators rated all participants in the experimental condition as having shown improvement in this category. The noted increase in self-efficacy for participant F was dramatic. In the pre-experiment interview, she was noted as expressing hesitancy. In the post-experiment interview, she said, "I'd like to learn another language—maybe be an interpreter." In the post-experiment interview, participant A said "My volunteering helps people. I feel a little better about myself." All participants in the experimental condition seemed energized—as observed by the research assistant during the interview and by participant comments—when talking about their volunteer experiences; all indicated that they were making a difference. Five of these participants expressed a desire to continue volunteering after the conclusion of the research project.

Of those participants in the control condition, one evaluator rated one participant as having declined in feelings of self-efficacy and being able to make a difference, three as having stayed the same and two as having improved in their feeling that they could make a difference. The second evaluator rated one participant as having declined, four as having stayed the same and one as having improved. In the post-experiment interview, one participant asked if what he had done in the study had made a difference. Partway through the study, this same participant asked if he could help transport another dialysis patient to treatments if this would not interfere with study results, as he was in the control condition. The desire to help transport never occurred because the patient to be transported died before the study participant was able to obtain his driver's license. One participant was rated by both evaluators as having declined in level of self-efficacy and perceived ability to make a difference. In the pre-experiment interview, this participant seemed to perceive himself as not being capable of making a difference; but, in the post-experiment interview, his expressed feelings of not being able to make a difference seemed intensified. The research assistant noted that he had a flatter affect in the post-experiment interview as he talked about not being able to perform his previous job anymore and sometimes feeling "hopeless." He said, "I worry about what I can't do anymore."

Observations by staff and others

The identities of participants in this research were not formally revealed to the dialysis staff; however, because of the small number of patients in the unit and the pride outwardly verbalized by the participants of the study while in the unit, many of the participants made their participation known. Informal observations of participants by staff members and verbal disclosures from participants and their family members to the principal investigator (PI) and the research assistant conducting the interviews were also considered. Five of the six participants in the experimental condition were noted as being more open and communicative at the dialysis center during and following their volunteer experiences. In support of this, all six were also noted by the evaluators as being more open and communicative in the post- as compared with the pre-experiment interviews. Another example: Before the start of the study, a participant in the experimental condition had requested an extended weekly time period with the social worker to discuss marital issues. Following the onset of the study, this participant was satisfied with a brief “hello” from the social worker. He reported that things were going well with his marriage and that his spouse approved of his volunteer experience. This participant’s spouse also requested continued volunteer experiences for the participant and expressed an increased respect in her view of the participant. When asked about setting up an appointment on a certain day, the participant responded, “I volunteer on that day.” The participant had originally requested a home-based clerical volunteer activity but, as this was not available, he agreed to try a placement outside his home. He continued successfully with this placement throughout the project.

A second participant in the experimental condition was not satisfied with the first volunteer experience outside her home. As her dissatisfaction became evident to the PI and the research assistant, she responded positively to the offer of a placement change. Following this change, she was noted by staff as becoming more talkative, open, self-assured and positive in attitude. After the start of the study, a third participant in the experimental condition was noted by the social worker as consistently offering handshakes in greeting. This behavior had not been noted prior to the study. The participant and spouse also verbalized enhanced marital satisfaction following the onset of the study. A fourth participant in the experimental condition, who had verbalized tendencies to show volatile behavior prior to the study, was seen to present a calmer affect following the onset of the study. A fifth participant in the experimental condition, who staff observed as being more communicative and open than ever observed before the onset of the study, expressed the desire to involve another family member in a volunteer experience. On the other hand, of the participants in the control condition, only one participant was observed following the onset of the study as displaying a more positive attitude while in the dialysis unit.

DISCUSSION

Volunteerism is an area that has not been investigated in the CKD population but has been shown to have demonstrable effects in elderly and chronic disease populations other than CKD (e.g., Musick & Wilson, 2003; Harris & Thoresen, 2005). The present study was intended to be exploratory and to contribute data upon which further research could be based and from which implications for practice can be considered. The findings of the present study show that volunteerism is an understudied phenomenon that can have a tremendous positive impact on dialysis patients. Those in the experimental condition of this study who volunteered weekly for 3 months showed significant improvement in adherence to dietary regimen, while those in the control condition who did not volunteer, as a group, did not improve on this measure of adherence to a dietary regimen that is critical to successful CKD treatment. Fluid weight gain, which is measured at each dialysis treatment, is most readily available to staff and patient and, thus, changes are very salient to patients. Further, it is a more accurate measure and more sensitive to patient dietary adherence than other measures. However, K and PO_4 levels are only measured monthly; while these are accepted measures and monthly measures are an accepted schedule for measurement, they are, consequently less reliable as an indication of adherence. Quantitative analysis of self-esteem and depression measures showed trends toward greater improvement for those in the experimental than in the control condition; these differences were not statistically reliable. However, the data from the quantitative analyses showed similar differences and indicate that a quantitative difference could be found in a larger sample than that observed in the present research.

The impact of volunteering was reported positively by all six participants in the experimental condition and was also observed in the affect, behavior and body language of a number of these volunteers. Five of the six participants in the experimental condition expressed a desire to continue volunteering after the project ended. Some talked about getting other people involved. All expressed enhanced self-perceptions of empowerment.

All participants in the experimental condition improved in their perceptions of their abilities to make a difference and self-efficacies. The resulting increase in sense of control over life is congruent with past studies of self-efficacy in that a belief that one can produce desired effects provides the incentive to act on these effects (Bandura, 1997). Accordingly, there was a significant improvement in adherence to dietary regimen by those in the experimental condition as compared with those in the control condition as shown by measures of fluid weight gain and K. Better adherence has a probable effect of improved patient outcomes and, thus, better results for dialysis providers.

The enhancement of relationships shown by those in the experimental condition resulted in creating more outside support for the participants. This likely played a role in helping them to deal with their illness as was indicated by the improved attitude toward dialysis shown by this group of patients. The participants were found to be more accepting and hopeful regarding their treatment. One participant volunteered along with his spouse. This created an opportunity for this couple to enhance their relationship by doing something meaningful outside the dialysis unit instead of being as focused on the participant's illness. Another participant's spouse requested that the participant volunteer even more in the future.

Aside from showing strong benefits of volunteering as it relates to the criteria measured in the study, there were also some unexpected benefits that resulted from the study. The dialysis unit studied, which was an independent unit at the start of the study, was incorporated by a large dialysis provider during the study. Many patients in the unit expressed anxiety about unknown and imagined changes and concerns surrounding this incorporation. At the time of the incorporation, there was concern by the PI, research assistant and consultant that the added stress expressed might influence the results of the study.

Instead, participants in the experimental condition demonstrated an ability to "weather" the stress and not let it affect their control of fluid intake, for example, as indicated by continuously improving lab results for April through June. Participants in the control condition showed a decline in their lab results for those months, which could likely be interpreted as a response to stress and the ensuing loss of control of their lives. Volunteer work was the single identified independent variable that was consistent in the lives of those in the experimental condition while not a factor in the lives of those in the control condition. This study indicates that volunteerism may have an added unexpected benefit of helping an individual to deal with stress.

Another unexpected positive byproduct of the present study was the noticeable decline in demand of extended social work time from the participants in the experimental condition. Prior to the study, two of the original seven participants in this condition routinely expressed marital dissatisfaction and requested frequent and lengthy social work intervention to help deal with these concerns. From the onset of the project, neither of these two participants expressed any marital concerns. Dialysis patients are faced with an inordinate amount of stress surrounding health concerns, loss of control and independence, loss of kidney function as well as relationship, financial and transportation concerns, among others. One effect of volunteering may be to provide a buffer to stress, which, in turn, may translate into less demand on the time of social workers and other staff members.

Benefits to society as a result of these participants' volunteer activities were also noted. A volunteer site representative from a nursing home shared how excited a resident was to have a weekly visit from one of the participants in the study. A representative from another volunteer site asked for permission to include appreciation for our volunteer in a newsletter. A highlight of the study was when a student at the Literacy Council, with the help of a tutor, wrote a personal note of appreciation to a study participant. Along with the note was a picture of his child—a child who, with the help of this project, has been able to enjoy her father reading a book to her.

As this study progressed, issues evolved that needed to be addressed to ensure its success. The PI was in contact with a representative from each volunteer site at the beginning of the study and as needed throughout the study. The research assistant was in periodic contact with each participant throughout the study. These planned contacts afforded participants the opportunity to express their level of satisfaction with their placements. When it was eventually realized that a participant in the experimental condition was unhappy with her placement, she took advantage of the opportunity to switch to another placement that was much more satisfactory to her. She continued her volunteer work after the fulfillment of her commitment to the project. This participant had not shared her dissatisfaction with the first placement until the site representative told the PI that attendance at the site had been sporadic. This information precipitated conversation with the participant, who then shared her concerns.

It was difficult finding home-based placements for those participants who preferred such placements. Of the original seven participants in the experimental condition, four requested home-based placements. A home-based participant who mended clothing in her home for an extended care facility (i.e., nursing home) needed someone to pick up and deliver the clothing. The PI created a partnership with a local Literacy Council that invited participants to read books on tape. There was a need to provide participants with books and cassette tapes and then deliver the finished product.

Limitations of the Study

The study had a small sample size. Thus, generalizations to any larger dialysis population are constrained. Additionally, the small sample size affects the reliability of the results. Examination of the findings from the quantitative measures in combination with the qualitative data from the interviews, however, suggests that the measures are valid. Volunteerism is an area that has received minimal attention for the CKD population and, consequently, this initial systematic attempt to examine its effect is important. In addition, there is a need for continued study of psychosocial determinants of adherence to dietary regimens for dialysis patients (Kutner, 2001; Pang et al., 2001). The indications of a positive effect of volunteering on adherence to dietary regimens and psychosocial health, even in a small group of patients, make the results of the present study invaluable.

Implications for Future Research

The Centers for Medicare and Medicaid Services (CMS) within the Department of Health and Human Services has revised requirements for Medicare certification for dialysis facilities (**http://www.cms.hhs.gov/CertificationandComplianc/05_DialysisProviders.asp#TopOfPage**). Rehabilitation is a critical component of the proposed revisions and addresses the need to restore "the mind and body to encourage the individual to maintain as full and active a life as possible." Moreover, the text suggests rehabilitation can benefit the patient, family and society in a myriad of ways that extend beyond simple return to employment. Examples indicate that rehabilitating the patient can allow a support person to return to the workforce, and that the improvement in the patient's quality of life may prevent long-term care facility placement and, ultimately, reduce medical costs. Findings from the present study support earlier claims that the volunteer experience has a positive impact on both the physical and mental health of older people in areas of general health decline and everyday functioning, depression and mortality rates (Lum & Lightfoot, 2005). It also supports previous claims that volunteering "can improve the health and mindset of those who do it" and that it can also "help people have better self-esteem at any age." One participant in the study perhaps best described the impact of volunteering when asked about her volunteer experience. She said, "It keeps my mind off me. I can't get down in the dumps trying to think about somebody else. I feel a little better about myself."

The findings of this study also suggest that volunteerism benefits a larger dialysis population. Findings also suggest the need for further research on the impact of volunteerism on the stress experienced by the CKD population, as well as on the reduction of time demands on staff to deal with patient concerns. Furthermore, previous research with other populations (e.g., Musick & Wilson, 2003) suggest a positive relationship between volunteerism and other physical factors, thus encouraging future research on the impact of volunteerism on physical factors experienced by dialysis patients (e.g., chronic pain, disability, mortality). The present exploratory study provides insight into the promising impact of a low-cost intervention on these critical issues. Further, the effects of various kinds of volunteer experiences (e.g., home-, community- and religious-based) were investigated. Finally, this study will assist in the development of an instrument to examine the impact of interventions on this population. It has already revealed areas important to these patients previously uninvestigated in the context of volunteerism.

Implications for Future Practice

The findings from this study about the benefits of volunteerism suggest that future dialysis social work interventions be expanded to include volunteerism activities as a standard of practice rather than an exploratory intervention as reported here. The present study suggests the addition of earmarked hours for either social workers or another individual with projected functions of promoting the benefits of volunteerism, locating volunteer opportunities, matching patients with appropriate volunteer placements, periodically monitoring the experiences and changing placement, if necessary. Findings from this study indicate that the additional time spent by staff in coordinating volunteer activities for patients may be more than compensated for by patients being less demanding of staff time because the patients feel more in control of their lives, experience elevated mood and decreased depression, enjoy increased social support resulting from improved relationships and are more adherent to their dialysis regimens. As an integral part of the dialysis team, social workers have specific functions, such as assisting patient adjustment to dialysis and the physical, psychological and social life changes that accompany the dialysis regimen. Social workers continually search for ideas and resources to help patients to continue to have a purpose in life, enhance their perceived control over their lives and function as productively as possible. It is frustrating for social workers to encourage patients to engage in traditional VR programs or apply for traditional employment at the same time that these patients need to wrestle with problems typical of dialysis, such as time commitment for dialysis, days of not feeling well and so forth. Unlike paid employment opportunities, volunteer opportunities are more likely to have a flexible time commitment that can incorporate dialysis treatment and frequent sick days.

Other possible benefits of volunteering may be that if patients gain more skills (social, technical, etc.), more confidence and enhanced feelings of self-efficacy from their volunteer experiences, they may become more marketable in the employment world. Thus, there may also be a byproduct of volunteerism leading to a desire on the part of some patients to enter more traditional VR programs and paid employment activities. Volunteerism can be either a viable alternative or an addition to traditional VR and paid employment activities. In short, when it comes to volunteering, "Nobody can do everything but everyone can do something."

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APPENDIX A

Interview Questions

1. How are things going for you?
2. How do you feel about your medical condition?
3. Tell me about taking care of yourself as the dialysis staff recommends.
4. How have your moods been lately?
5. How have you been getting along with the people in your life who matter to you?
6. How are you feeling about yourself?

APPENDIX B

Volunteer Opportunities

- Answering phones for a local helping organization
- Calling shut-ins to check that they are doing “OK”
- Helping at a local food bank/pantry: stocking shelves, helping customers, cleaning, etc.
- Visiting a lonely resident at a local nursing home
- Teaching or making a craft
- Audiotaping books for clients of a literacy council
- Writing letters to residents of nursing homes, prisons and schools
- Mending clothes for the sick and elderly
- Clipping coupons for patients in the hemodialysis unit, the elderly or a school or church

New Legislation and Old Solutions: Employment Following Renal Transplantation Revisited

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Employment (i.e., return to work) and renal replacement therapy have been linked since the original discussions for the 1972 Social Security Amendment. This legislation deemed individuals with end-stage renal disease disabled for the purpose of Medicare eligibility and access to treatment. Proponents of the legislation suggested that 60% of those who received renal replacement therapy would resume employment following vocational rehabilitation, and the majority of the remaining 40% would return to work with no intervention (Kutner & Brogan, 1985; Rettig, 1984). Achieving this optimistic prediction has been elusive, and post-transplant employment outcomes have been disappointing. Nevertheless, the number of renal transplants has risen yearly, with 17,094 transplants being performed during 2006, 80.8% for individuals ages 18 to 64 (Organ Procurement and Transplantation Network, n.d.[a]). Thus, the majority of patients who undergo renal transplantation are working-age adults and many do not return to the labor force.

INTRODUCTION

Legislative action was taken as awareness increased that the current disability system is limited in returning individuals with disabilities to work. The 1999 Ticket to Work and Work Incentives Improvement Act targeted barriers to employment for individuals with disabilities (Callahan, 2005). It was also intended to supplement traditional vocational rehabilitation (VR) services, whose record of returning eligible individuals to work was less than 0.5 percent (General Accounting Office [GAO], as cited in Growick, 2001). Ohio was in the final phase of implementing the Ticket program, which began in November 2003. The Ticket program, coupled with advances in medically managing individuals following transplantation, has the potential to improve employment outcomes. To determine the current employment status of kidney transplant patients, a research study was designed to answer the following questions:

1. What is the employment status of individuals, post-transplant?
2. What is the rate of participation in the Ticket to Work Program?
3. What is the relationship between participation in the Ticket to Work Program and employment, post-transplant?
4. What factors predict post-transplant employment?

PREVIOUS LITERATURE AND THEORETICAL FRAMEWORK

Post-Transplant Employment

Employment following kidney transplantation has historically, and consistently, been lower than was predicted when the policy was enacted. Post-transplant employment in the United States ranges from 29 to 71%, although measurement of employment and sample characteristics have been quite variable (van der Mei et al., 2006). Additionally, studies have found that the percentage of individuals who claim the physical ability to work post-transplant is consistently larger than those who are actually employed (Manninen et al., 1991; Raiz, 1996).

Generalizations regarding predictors of employment are hindered by issue, such as limitations of some of the research designs (see van der Mei et al., 2006). One variable consistently associated with post-transplant employment is employment status prior to transplant (Evans et al., 1991; Jones et al., 1993; Matas et al., 1996; Raiz, 1996). Without exception, studies document that individuals who are employed prior to transplantation are more likely to be employed post-transplant. Other factors associated with post-transplant employment include age (Evans et al., 1991; Raiz, 1996), health status (Evans et al., 1991), education level (Evans et al., 1991), diabetic status (Jones et al., 1993; Matas et al., 1996) and transplant source (Jones et al., 1993). Younger recipients, non-diabetics, living donor recipients and those with higher levels of education are significantly more likely to be employed following transplantation. It has been suggested that factors beyond the clinical medical indicators (such as the creatinine level in a patient's blood) are related to employment (Callahan, 2005; Manninen et al., 1991; Matas et al., 1996; Paris et al., 1997). The biopsychosocial model provides a framework for exploring post-transplant employment from a holistic, patient-centered perspective.

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The Biopsychosocial Model

In 1977, George Engel introduced the biopsychosocial model to address what he considered to be limitations of the traditional biomedical model. He noted that the biomedical model precludes acknowledging "the social, psychological, and behavioral dimensions of illness" (Engel, 1977, p. 130). Engel cautioned that because "laboratory documentation" could reflect only the potential for disease, it was necessary, though not sufficient, to assure the "human experience" of disease (p. 131). Engel concluded by challenging medicine to view disease, and its manifestations, from a holistic perspective.

> To provide a basis for understanding the determinants of disease and arriving at rational treatments and patterns of health care, a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of the illness, that is, the physician role and the health care system (p. 132).

By applying systems theory (Borrell-Carrió et al., 2004), the biopsychosocial model recognizes that biological, psychological and social factors interact to contribute to the human experience of sickness and wellness (Suls & Rothman, 2004). Thus, it is necessary to identify and address factors within each dimension of the model to successfully understand the sickness/wellness continuum and provide appropriate services. Environmental barriers to employment for individuals with disabilities generally, and those following transplantation specifically, provide examples of the importance of a social factor. Examples of social factors that may be related to employment following renal transplantation are disability policies and time limits for Medicare coverage of immunosuppressants.

The Ticket to Work and Work Incentives Improvement Act

The Ticket to Work program was created to increase employment for individuals with disabilities (Growick & Drew, 2003). Return to work (RTW) rates of individuals with disabilities historically had been suboptimal, as reflected in the 1996 report from the GAO. It stated that beneficiaries were more likely to die or retire than to return to work (as cited in Growick & Drew, 2003). Concerns regarding the process of determining disability have been explicated. They include the requirement only in the United States that an individual is totally incapable of working at the time of disability evaluation to be considered disabled. It ignores the issue of rehabilitation potential at the time disability is determined (Drew & Growick, 2004). The disconnect between determining disabled status and initiating RTW activities has been cited as an important area for change (Growick & Babson, 2005). Also, it has been suggested that rehabilitative services begin at the time of disability evaluation (Growick & Drew, 2003).

Another limitation of the disability and rehabilitation system is the "order of selection" created by the Rehabilitation Services Administration more than two decades ago (Growick, 2001). It established a hierarchy for receiving rehabilitation services based on the disability severity (Growick, 2001). Those with the most severe disabilities received services most quickly, leaving individuals with comparatively lesser disabilities with delayed service initiation.

Both issues—the disconnect and the order of selection—have important implications for individuals undergoing renal transplantation. Once renal replacement therapy is initiated, individuals are deemed "disabled" for the purpose of Medicare eligibility; however, an additional application for Social Security Disability is required for full disability benefits. There is variability concerning the date of eligibility, depending on the type of renal replacement therapy. Individuals who undergo transplantation are eligible for Medicare immediately upon transplantation and those who receive dialysis are eligible either immediately (in the case of peritoneal dialysis patients), or after 3 months of treatment (in the case of hemodialysis patients).

RESEARCH METHODS

Sampling

Individuals who underwent solitary renal transplantation during the five-year period from January 1, 2000 to December 31, 2004 were eligible to participate in this study. Additional eligibility criteria of having a functioning graft at the time of the study and not being lost to follow-up resulted in a final sampling frame of 734. A modified Dillman's method for mailed survey was used to collect data. The instrument, a cover letter, consent form and self-addressed, stamped envelope were mailed to all eligible individuals. A reminder postcard was subsequently mailed, followed by a second mailing to nonresponders.

Instruments were returned by 286 individuals, for a response rate of 40.2%. The 166 respondents under age 65 with complete data who were included in the final regression analysis were compared first to all responders ($n = 286$) and then to the total sample ($n = 734$). Diabetic status, type of donor, education level, Medicaid status, race and sex were not significantly different between the final sample and all respondents. However, those included in the final analysis were significantly ($p < 0.001$) younger and more likely to have been employed prior to transplant and at the time of study participation than those excluded. Individuals included in the final regression also had significantly higher ($p < 0.05$) self-perceived physical functioning and significantly lower ($p < 0.05$) perceived mental health functioning. Additional analyses revealed that age ($p < 0.05$) and donor status ($p < 0.01$) of the final sample were significantly different from all who met eligibility criteria ($n = 734$). The final sample was younger and composed of more individuals who received living-related donations and fewer organs from deceased donors. Diabetic status, race and sex of the two groups were not significantly different.

Measures

Eighteen variables in this study included 1 outcome variable (employment status) and 15 predictor variables, which were used in the multivariate analysis. The two additional variables were participation in the Ticket to Work program and VR participation. Employment was measured with one item that asked about "employment status at this time." The three response options were: not employed, employed part-time and employed full-time. A single, dichotomous item asked whether respondents had ever received a Ticket to Work from Social Security and another asked whether they had ever participated in VR. The original intent was to include participation in the Ticket program and VR in the multivariate analysis to predict employment, but there was insufficient variation among the final sample to use them. Nevertheless, because they directly addressed research questions two and three, results are reported and discussed. As previously mentioned, the biopsychosocial model guided determination of variables used in the multivariate analysis. Table 1 presents the variables used in the regression analysis for employment post-transplant.

Table 1.

Variables Used in the Regression for Post-Transplant Employment

Biological	Psychological	Social
Age	Infection problems	Education completed
Creatinine	Mental Health (SF-36)	Employment status pre-transplant
Diabetic status	Physical Function (SF-36)	Medicaid status
Donor type	Sleep problems	Medicare status
Race	Stomach problems	
Sex		

Six variables comprised the biological dimension: age at the time of study participation (years and months), creatinine (average creatine of 90 days), diabetic status (no/yes), donor type (deceased, living), race (African American, Caucasian) and sex (female, male). One could debate placement of age, race and sex in the biological category as their relationship with employment may also derive from their social (cultural) importance. However, it was decided to define them as biological due to their classification, in discussions of human diversity, as primary characteristics and not within control of the individual (Lum, 2000). These visible, given traits are distinguished from traits that are within control of the individual and usually not visible (Lum, 2000).

Five variables represented the psychological domain: self-perceived physical functioning and mental health as measured by the SF-36 subscales (Cronbach's 0.943 and 0.849, respectively) and self-perceived problems with infection, sleep and stomach measured by the Memphis Survey. The Memphis Survey was created to examine the effect of immunosuppressant medications (Winsett et al., 2004). It lists a number of conditions associated with immunosuppressants and invites respondents to report whether they experience each condition and how "troubling" it is. A 5-point Likert-type scale was used. Scale scores are calculated with a 4-step process, as instructed by the survey developers. The 6 gastrointestinal items were combined to create a stomach scale with a Cronbach's of 0.701. The items were stomach pain, nausea, diarrhea, vomiting, stomach gas and indigestion. Infection and sleep were measured with single items.

Four single items represented the social domain: education completed, employment status 1 week prior to transplant (employed/unemployed), Medicaid status (no/yes) and Medicare status (no/yes).

RESULTS

Table 2 presents demographics for the final sample of 166. The majority was male, Caucasian, married and received kidneys from living donors. The mean age was 50 with a range from 22 through 64. More than 60% had education beyond high school. The overwhelming majority did not have Medicaid and a majority did not have Medicare, although the difference between those with and without Medicare was not large.

Table 2

Sample Demographics (n = 166)

Variable	Number (*n*)	Percentage (%)
Donor Type		
Living related	57	34.1
Living unrelated	45	26.9
Deceased	65	38.9
Education Completed		
High school	60	35.9
Some college	34	20.4
Associate/ vocational degree	23	13.8
Undergraduate degree	34	20.4
Graduate degree	15	9.0
Medicaid Insurance		
No	145	86.8
Yes	22	13.2
Medicare Insurance		
No	90	
Yes	77	
Race		
African American	20	12.0
Caucasian	146	88.0
Relationship Status		
Divorced	19	11.4
Married	113	68.1
Separated	6	3.6
Single	16	9.6
Widowed	4	2.4
Living with partner	8	4.8
Sex		
Female	59	35.5
Male	107	64.5

Nearly one-half (48.2%) of respondents reported full-time employment and another 9.6% part-time employment at the time of study participation, resulting in an employment percentage of 57.8. Participation in the Ticket to Work program was reported by 12.8% of the sample (*n* = 21). Full-time employment was reported by 2 individuals and part-time employment reported by 4 respondents who participated in the Ticket to Work program. The majority of those who indicated participating in the Ticket to Work program at some point prior to study participation (71.4%) reported being unemployed.

The results of the hierarchical regression analysis are presented in Table 3. The biological variables entered in the first step contributed 6.8% of the variance in employment status post-transplant. Only the –0.272 coefficient for diabetic status was significant at the 0.01 level. The coefficient indicated that individuals with diabetes were significantly less likely to be employed. The second step resulted in an F change of 12.72 (p <0.001) with 31.9% of the variance explained. Of the 5 psychological variables, perception of physical functioning was the only one that contributed significantly to the model. Diabetes retained its importance in the second step. The final step, which introduced the social variables, explained 66.6% of the variance and resulted in an F change of 40.90 (p <0.001).

Table 3

Regression of Biological, Psychological and Social Variables on Employment Status Post-Transplant

Variables	*B*	SE *B*	β
Step 1			
Biological			
Age	-0.009	0.007	-0.095
Creatinine	-0.113	0.095	-0.092
Diabetic status	-0.602	0.172	-0.272**
Donor type	0.171	0.157	0.088
Race	-0.083	0.122	-0.057
Sex	0.126	0.152	0.064
Adjusted R^2 = 0.068			
F Change = 3.016**			

Continued on next page

Table 3 Continued

Step 2			
Biological			
Age	-0.001	0.007	-0.015
Creatinine	0.011	0.084	0.009
Diabetic status	-0.316	0.160	-0.143*
Donor type	0.128	0.136	0.066
Race	-0.068	0.106	-0.047
Sex	0.150	0.139	0.076
Psychological			
Physical functioning	0.015	0.003	0.460***
Mental health	0.006	0.004	0.128
Infection problems	-0.098	0.073	-0.101
Sleep problems	-0.033	0.052	-0.047
Stomach problems	0.032	0.019	0.129
Adjusted $R^2 = .319$			
F Change = 12.716***			
Step 3			
Biological			
Age	0.000	0.005	-0.005
Creatinine	-0.015	0.059	-0.012
Diabetic status	0.022	0.116	0.010
Donor type	0.009	0.099	0.004
Race	0.046	0.075	0.032
Sex	0.204	0.099	0.103*
Psychological			
Physical functioning	0.008	0.002	0.246***
Mental health	0.004	0.003	0.087
Infection problems	-0.0052	0.051	-0.053
Sleep problems	-0.020	0.037	-0.028
Stomach problems	0.042	0.013	0.167**
Social			
Education completed	0.040	0.032	0.059
Employment status	1.065	0.110	0.560***
Pre-Transplant			
Medicaid status	-0.008	0.155	-0.003
Medicare status	-0.354	0.103	-0.186**
Adjusted $R^2 = .666$			
F Change = 40.897***			

*$P<0.05$; **$P<0.01$; ***$p<0.001$.

The final model identified factors related to post-transplant employment status. The most important was employment status 1 week before transplantation (0.560) followed by patient perception of physical functioning (0.246). Medicare status was next in importance (–0.186), followed by patients perceiving stomach problems (0.167) and respondents' sex (0.103). In this sample of patients, important predictors of employment following transplantation were employment prior to transplant, perception of better physical functioning, lack of Medicare insurance, report of less trouble due to stomach problems and being male.

Because employment status 1 week prior to transplant was such an important predictor of post-transplant employment, further examination was conducted. Table 4 presents the relationship between employment status prior to transplant and prior to onset of end-stage renal disease (ESRD) and employment at the time of study participation. Significant differences (p <0.001) in current employment were related to employment status both 1 week prior to transplantation and pre-ESRD.

Table 4

Relationship Between Prior Employment Activity and Current Employment Status

Current Employment Status	If Employed Pre-ESRD (*n* = 95)	If Employed Pre-Transplant (*n* = 8 9)	If Employed Pre-ESRD and Pre-Transplant (*n* = 72)
Not employed	24 (25.3%)	7 (7.9%)	5 (6.9%)
Employed part-time	8 (8.4%)	10 (11.2%)	8 (11.1%)
Employed full-time	63 (66.3%)	72 (80.9%)	59 (81.9%)

The group of individuals who were employed prior to the onset of ESRD and 1 week prior to transplantation presented with the largest percentage of post-transplant employment. Their combined full- and part-time employment was 93.0%. However, only employment 1 week prior to transplant resulted in post-transplant employment (combined full- and part-time) of 92.1%. Finally, nearly three-fourths of those employed pre-ESRD were employed post-transplant.

The employment status of those unemployed prior to ESRD and/or transplant also was examined. Table 5 presents the employment status for those with no employment pre-ESRD and/or pre-transplant. More than 80% of those unemployed during any time prior to the transplant remained so following transplantation.

Table 5

Current Employment Status for Individuals Reporting No Employment Pre-ESRD and/or Pre-Transplant

Current Employment Status	If Not Employed Pre-ESRD (*n* = 49)	If Not Employed Pre-Transplant (*n* = 77)	If Not Employed Prior to ESRD or Transplantation (*n* = 46)
Not employed	41 (83.7%)	63 (81.8%)	39 (84.8%)
Employed part-time	5 (10.2%	6 (7.8%)	4 (8.7%)
Employed full-time	3 (6.1%)	8 (10.4%)	3 (6.5%)

STUDY LIMITATIONS

Surveys were sent to all eligible individuals, but the final sample was self-selected. It consisted only of those individuals who completed and returned questionnaires. As previously mentioned, the final sample had characteristics significantly different from all individuals who completed the survey and all 734 eligible to participate in the study. Further, the final sample included only those under age 65 with a functioning graft. Thus, representativeness of the final sample and generalizability must be evaluated with these caveats (Rubin & Babbie, 2005).

The outcome of interest—employment—is dynamic, as are some of the predictor variables. Respondents were asked about employment status only at the time of study participation. Thus, only a point-in-time representation of employment is provided. This estimate may be too high, or low, as individuals transition in and out of the labor force. However, this potential concern may be diminished by disability policies related to employment and eligibility criteria for Medicare and Medicaid that constrain frequent changes in employment status for those receiving disability. However, the cross-sectional nature of this design limits examination of causal relationships. Longitudinal research, ideally at multiple points along the ESRD process, will address this limitation.

Finally, it was not possible to examine fully the relationship between participation in the Ticket to Work program and employment status due to the low number of respondents who reported participation in the program. Perhaps this resulted from the relatively recent implementation of the program in Ohio. Future research should revisit participation in the Ticket to Work program and associated outcomes, ideally with a longitudinal time dimension.

DISCUSSION

Two unexpected results emerged in this study, which was largely intended to investigate the relationship between participation in the Ticket to Work program and post-transplant employment. The first was the dismal participation in the Ticket to Work program. The second was the dramatic demonstration of the importance of pre-transplant employment.

The low rate of participation in the Ticket to Work program precluded meaningful investigation of its relationship with employment. However, the low rate of participation, itself, was a disconcerting finding. One explanation could be the relatively recent implementation of the program in Ohio. Data for this study were collected nearly 3 years after the 2003 rollout in Ohio. An area for future research is the extent of participation by individuals with ESRD. If the findings are consistent with those of this study, investigation of contributors to low participation is warranted. Because one explanation of the low participation rate could be the somewhat recent implementation of the Ticket to Work program, participation in traditional VR by respondents in this study was examined. Once again, only 12.1% of the final sample received VR. Eight individuals participated in both VR and Ticket to Work. Thus, an additional 12 individuals participated in only VR. This, too, presents a disturbing picture, one that requires further exploration. It appears that almost all respondents in this study did not participate in the Ticket to Work program or VR and the few who did so did not achieve the desired outcome of employment.

The percentage of those in this study with full- or part-time employment following transplantation (57.8%) was larger than the previously reported 35.8% full- or part-time employment of 636 individuals with a functioning renal graft post-transplant (Matas et al., 1996). It also was greater than the 43.4% employed reported by Evans et al. (1991). The weight of employment status prior to transplantation cannot be overstated. It echoes findings in studies dating back 25 years. Evans et al. (1991) found that age, health status, education level and employment status during the year pre-transplant were related to post-renal transplant employment. Jones et al. (1993) reported that pre-transplant employment was an important predictor of employment following transplantation and suggested that employment status often remains consistent following transplant. Pre-transplant employment and diabetic status were the only factors predictive of post-transplant employment for 636 individuals 1 to 9 years following renal transplantation (Matas et al., 1996). In the previously mentioned studies, individuals employed prior to transplantation were more likely to be employed following the transplant. The importance of employment status prior to transplant becomes even more compelling when one examines the consistency of employment status throughout the course of ESRD.

When examining those employed prior to transplant and prior to renal failure, employment percentages are even more impressive. In fact, they actually approach estimates of post-transplant employment offered by proponents of the original legislation in 1972. This suggests an important consideration for research and practice. Researchers must attend to the heterogeneity that exists with regard to employment status prior to transplant, even prior to renal failure. At a basic level, when simply describing employment status post-transplant, researchers (and transplant centers) should identify which group of individuals they are examining. Data should be collected that informs not only pre-transplant employment status, but also employment pre-ESRD. One would not anticipate the same employment outcomes for those working until transplantation and those detached from the labor force for longer periods of time.

Further, attempts to identify factors related to employment should consider when the individual ceased employment during the ESRD disease process. There are multiple contributors to detachment and attachment to the labor force, which may affect those at various stages of the ESRD/transplant continuum differently. In fact, some factors important at one stage may decrease in importance, or even disappear, at another stage. For example, biological factors may take precedence when an individual begins dialysis. At that time, physical adjustment to treatment as well as symptoms related to the disease and side effects of dialysis may have an important role. However, psychological and social factors may become more important to individuals with a functioning graft following transplantation.

The biopsychosocial model guided analysis of contributors to employment following renal transplantation. Interestingly, the dimension that made the least contribution to the final model was biological. While this may appear counterintuitive at first glance, these findings, once again, suggest that individuals post-transplant are not a homogenous group. The individuals in this study had well-functioning grafts, as reflected in their creatinine levels. It appears that those whose kidneys are functioning well post-transplant may benefit from interventions that address more holistic issues. The one biological variable, diabetes, that significantly contributed to employment initially, lost its importance in the final model that included psychological and social variables. Patient perception of physical functioning was the second most important predictor of post-transplant employment. Another psychological variable, the trouble individuals perceived related to stomach problems, also was important. These factors suggest that it is the experience of illness and wellness, as perceived by the patient that is important versus an objective clinical indicator, such as a lab value.

Social work interventions should be initiated to address factors appropriate for individual circumstances. Dialysis and transplant social workers should develop protocols to direct assessment and intervention based on whether an individual is employed at the time of first contact and the point in time the individual became detached from the labor force. A standard employment assessment tool could be a distinct component of the psychosocial assessment, and include biological, psychological and social dimensions known to be associated with employment. Social workers, in this field of practice, have unique training in investigating the patient experience of ESRD and its relationship to employment, particularly at different points in the illness/wellness continuum. Thus, the services provided for a patient who had not been employed for months, or years, prior to the onset of ESRD may be quite different from services for an individual detached from the labor force while undergoing hemodialysis.

Dialysis social workers also can appreciate the importance of maintaining employment for those working at the time of ESRD. Labor force detachment may occur during the days one waits for a kidney from a deceased donor, considering that the median waiting time, during 2001 to 2002 was 1,636 days for individuals between the ages of 18 and 64 (Organ Procurement and Transplantation Network, n.d.[b]). Therefore, dialysis social workers should educate patients about the importance of maintaining employment, if possible; help patients understand their rights and protections under the Americans with Disabilities Act; and most certainly advise patients about RTW services, such as Ticket to Work. Social workers should also advocate for patients within the dialysis center (for schedules that promote employment) and in the community (for receipt of VR in a timely fashion). It is incumbent upon nephrology social workers to be knowledgeable about the Ticket to Work services in their communities, initiate the appropriate referrals and advocate for receipt of RTW services, despite barriers such as the order of selection.

While the biopsychosocial model provides a sound framework from which to study important outcomes in transplantation, such as employment, each component of the model needs further specification. The component that currently may be most developed, biological, may not be the most important to employment. Researchers should include all biological variables previously shown to be associated with non-biological outcomes of interest (e.g., employment and quality of life). Additionally, theory and previous findings should advise utilization of variables from the psychological and social dimensions. These are the domains in which social workers possess expertise and the ability to advocate toward the desired outcomes.

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Kidney Community Emergency Response (KCER) Coalition: Partnering to Improve Prepardness and Outcomes in Disasters

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Emergency events that could occur nationwide and affect the renal community include earthquakes, fires, floods, blizzards, hurricanes, tornados, ice storms, chemical spills, pandemic disease and acts of terror. Each emergency has the potential to affect access to care. Facilities should be prepared to address concerns such as lack of power, water, food, housing and communications; dangerous conditions; flooding; fuel shortages; patient tracking issues; mass zone evacuations; rapidly changing weather; road closures and patient transportation issues; curfews; hospital closures and limited staff resources. Providers should be prepared to assist patients with little or no notice. The Kidney Community Emergency Response Coalition is working together to minimize disruption to life-sustaining dialysis and transplant services in emergencies.

INTRODUCTION

The Kidney Community Emergency Response (KCER) Coalition is represented by patient and professional organizations; practitioners; providers, including independent dialysis facilities, large dialysis organizations and transplant facilities; hospitals; suppliers; end-stage renal disease (ESRD) networks; state emergency and survey representatives; and federal agencies. These organizations are committed to assisting state and local responders in meeting the life-saving medical needs of individuals with kidney failure under all circumstances. Through the collaborative efforts of the KCER partners, the goals of the coalition are to:

- raise public awareness of the critical needs of individuals with kidney failure, the providers that service them, and the need to plan ahead to ensure life-saving services are available/obtainable
- promote and disseminate tools and resources for individuals with kidney failure, dialysis facilities, transplant facilities and key partners in emergency response at the federal, state and local level
- plan for a possible flu pandemic
- test and refine a national response strategy to assist federal, state and local efforts in the event of an emergency and/or disaster.

KCER's activities, in partnership with Centers for Medicare & Medicaid Services (CMS), have contributed toward significant changes in regulatory requirements, including proposed new emergency preparedness and response language in the ESRD Conditions of Coverage, which are under revision with an early 2008 target date for final rule publication. Additionally, the new ESRD Network contract includes clear requirements for every Network to have in place plans for disaster response. This article provides a review of the history of the formation and development of KCER, information on the coalition's continued efforts toward improved processes and a discussion about how social workers can be a part of the emergency response and help save lives in the kidney community.

BACKGROUND: KCER PHASE I

The severity of the 2004 Florida hurricane season and the effect it had on the Florida renal community was unexpected and unprecedented. Four hurricanes—Charley, Frances, Ivan and Jeanne—affected Florida, making it the only state since 1886 to sustain the impact of four hurricanes in one season. These four hurricanes made landfall in the state within 45 days and caused a large portion of the dialysis community to be unable to function normally. Hurricane Charley made landfall on August 13 as a category 4 hurricane just north of Captiva, FL, struck the city of Punta Gorda and neighboring Port Charlotte with devastating results, continued across the Florida peninsula and exited the state at Daytona Beach. Charley came ashore again near

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Cape Romain, SC, on September 14 as a weakening hurricane, moved just offshore, made landfall at North Myrtle Beach, SC, then weakened to a tropical storm over southeastern North Carolina. Approximately 90 Florida facilities were in the path of Charley; 25 were left without power and/or water and another 4 facilities had significant damage. Patients from the downed facilities were redirected to other local dialysis centers for treatment and two dialysis units were approved for addition to dialysis stations to accommodate displaced patients.

Hurricane Frances hit Florida on September 4. Because of the size and the predicted path, practically the entire state was at risk. The CMS Atlanta Regional Office established a response team to assist providers with any questions regarding the billing process for patients who might be receiving services temporarily in a facility due to the hurricane. The Agency for Healthcare Administration (state agency) coordinated preparedness and response efforts with FMQAI: The Florida ESRD Network (Network 7). Based on lessons learned from Charley, off-site contact numbers and alternate e-mail addresses were shared among Network staff, state agencies, emergency responders and providers to facilitate after-hours contact and/or contact with individuals who may have been evacuated from their usual office/facility location. When the storm was approaching, Florida providers dialyzed patients, with many of the facilities providing treatments throughout the night. Due to the slow forward motion of Frances, facilities were planning to be closed for at least 2 days. Frances made landfall as a category 2 hurricane over the southern end of Hutchinson Island, FL. Frances moved slowly across the Florida Peninsula, emerged into the northeastern Gulf of Mexico near New Port Richey, then made landfall again in the Big Bend region of Florida. Frances headed northeast over eastern Alabama and western Georgia, weakened, and continued over West Virginia, across New York and northern New England with gale-force winds. In Florida, 84 units lost power, water or both due to Frances. Many patients did not receive treatment for 2 to 3 days, and because of the limited number of functioning facilities, patients were triaged and dialyzed based on need. Very few units were able to open along the Florida's east coast, from Melbourne south to West Palm Beach. Two facilities received major damage forcing them to close indefinitely: a north Florida facility with sinkholes surrounding the unit and another in southwest Florida that had its new roof (repaired from Charley) torn off.

Hurricane Ivan made landfall just west of Gulf Shores, AL, on September 16 as a category 3 hurricane, and resulted in strong winds over a narrow area near the southern Alabama-western Florida panhandle border. After Ivan moved across the barrier islands of Alabama, it crossed Mobile Bay and into central Alabama. Ivan continued over the northeast, causing flash floods and tornado damage across much of the southeastern United States. Ivan looped back and crossed the southern Florida peninsula from the Atlantic and then the Gulf of Mexico on September 21, then crossed Mississippi and southwestern Louisiana as a tropical depression, finally dissipating over the upper Texas coastal area on September 24.

The Florida ESRD Network began monitoring reports from the Emergency Operations Center related to Hurricane Ivan less than 1 week following Frances. Although facilities were still recovering from Hurricane Frances, Network 7 hosted a preparedness conference call, with 170 Florida providers participating. Three facilities affected by Hurricanes Charley and Frances shared lessons learned and best practices. A Special Open-Door Forum was also arranged and hosted by CMS to discuss the significant hurricane relief efforts in Florida, how to make a difficult situation as uncomplicated as possible and plan for continued quality care for kidney patients during and after the storm. As Ivan's uncertain track left the entire Gulf Coast in harm's way, Network 7, at the request of CMS, conducted a "Best Practices/Lessons Learned" session with ESRD Networks 6, 8, 13 and 14. CMS and state agencies for each of the states that might be affected were also on the call.

When Ivan hit Florida on September 21, it remained on land for more than 12 hours. Eleven Florida facilities reported being unable to operate due to Ivan. ESRD Networks 6 and 8 partnered with Network 7 to help patients and facilities by identifying units that were open for treatment. One facility requested that water be brought to them to dialyze patients. A nonaffiliated corporate group assisted the facility by sharing a water tanker truck they had on stand-by. A guide for water treatment during a "Boil Water Alert" was distributed to the affected providers as a resource.

Hurricane Jeanne appeared as a threat to the east coast of Florida within a week of Ivan. Jeanne made landfall on the east coast of Florida on September 26 as a category 3 hurricane, moved across central Florida, then northward across central Georgia, the Carolinas, Virginia and the Delmarva Peninsula. In the aftermath of Jeanne, an initial status check found 45 Florida facilities without power and/or water or damaged. Five of these facilities had been damaged from previous 2004 hurricanes.

In response to lessons learned in 2004, CMS awarded Network 7 a special study: "Developing Strategies and Strategic Partnerships to Overcome Disasters." The purpose of this study was to help other ESRD Networks in their disaster planning for patients, providers and stakeholders. Activities conducted included:

- development of a best-practice checklist for use by ESRD Networks
- a mock disaster drill with the expectation that all ESRD Networks respond as they would in a real disaster
- a disaster-readiness survey distributed to all Networks, to assess and measure their perceived emergency preparedness level.

Hurricane Katrina hit in the early stages of the study, and led to expansion of the scope of the project. Katrina caused damage on August 25, 2005 in southern Florida as a category 1 hurricane, emerged into the southeastern Gulf of Mexico, gained strength to a category 5 hurricane, turned northward toward the northern Gulf Coast, around the ridge over Florida, then made landfall as a category 3 near Buras, LA, on August 29. Katrina continued northward and made its final landfall near the mouth of the Pearl River at the Louisiana/Mississippi border. Katrina weakened rapidly after moving inland over southern and central Mississippi, becoming a category 1 hurricane. It weakened to a tropical storm just northwest of Meridian, MS, before moving over the southeastern United States, the Tennessee Valley and the Great Lakes. In anticipation of Katrina, ESRD Networks 7, 8, 13 and 14 contacted providers and reminded them to implement their emergency plans. Emergency contact numbers were sent to providers along with reminders to advise the Networks of any damage or assistance needed. Patients were dialyzed in advance of the hurricane's predicted landfall. Pre-landfall in Louisiana, CMS, Network 7, the American Nephrology Nurses Association and the National Renal Administrators Association planned strategies to assist affected Networks with coordination of staffing needs/volunteers, patient tracking, exchange of key medical records and identifying/listing facilities as open or closed. When Katrina hit on August 29, it affected the operation of 94 facilities, (9 in Alabama, 31 in Mississippi and 54 in Louisiana). Approximately 5,849 dialysis patients were in the affected areas. Katrina also impacted accessibility to renal transplant care (transplantation, access to anti-rejection medications and physician follow-up, etc.). Network 8's office in Jackson, MS, lost power, telephone service and Wide Area Network capability for 4 days, moving to an alternate location to conduct response efforts. The majority of patients—more than 600 dialysis patients—fled to Texas.

Network 14, which serves Texas, was assisting Katrina evacuees while under the threat of Hurricane Rita, which struck near the Texas/Louisiana border as a category 3 hurricane on September 24. Rita produced significant storm surges that devastated coastal communities in southwestern Louisiana, and its winds, rain and tornadoes caused fatalities and a wide swath of damage from eastern Texas to Alabama. Additionally, Rita caused floods due to storm surge in portions of the Florida Keys. Assisting displaced patients was difficult, as many had multiple relocations because of evacuation route and shelter changes. Locating shelters close to available dialysis services posed a challenge. An even bigger challenge was the task of arranging and coordinating transportation. ESRD Networks 7, 8, 13 and 14 assisted patients in locating facilities and resources and served as a communication conduit for the renal community and state, federal and local emergency workers. Industry stepped in to assist with supplies. The National Kidney Foundation (NKF) established a listserv for the kidney community and key partners, and Network 13 hosted daily community-wide conference calls. The renal community learned important lessons from Hurricanes Katrina and Rita, and it was imperative to include these efforts as part of the project. Plans for a National Disaster Summit began.

The National Disaster Summit convened on January 19, 2006 in Washington, D.C., to review disaster response in the ESRD community, plan for the future and explore interest in the formation of a national coalition. Eighty participants—residents of 25 states and the District of Columbia—shared in planning for national strategic responses and priority action areas. Participants decided to form a national coalition, later named the KCER Coalition. Eight response teams were established to address patient assistance, volunteer coordination, physician assistance, communications, patient and facility tracking, facility operations, federal response and industry supplies/services. A Strategic Planning Committee was formed with representatives from each response team. Phase I of the KCER included the development and initial dissemination of tools and resources to help patients, facilities, emergency responders and coalition members plan for and respond to emergencies and disasters. The NKF was the administrative lead responsible for coordinating Coalition activities during Phase I.

KCER PHASE II

Network 7 assumed the lead for administrative support of the KCER in Phase II and convened the second KCER Summit on March 1, 2007 in Baltimore, MD. There were 120 Summit participants, residing in 32 states. ESRD Networks 2, 12, 13, 14 and 17 shared lessons learned from 2006 regional disaster experiences (snowstorms, sudden wind storms, ice storms, a facility fire, tornadoes and severe flooding), with emphasis on all hazards. Network 7 led a tabletop mock disaster drill to test kidney community response mechanisms and aid in planning for Phase II activities. The drill aided the response teams in identifying issues, priorities and gaps in response mechanisms. Some areas of improvement identified included: further definition of KCER roles and processes in emergency response; continued work with the National Disaster Medical System to develop a federal response capacity to provide nephrology staff for emergency events; strengthened processes of communication/coordination with state agencies, ESRD Networks and CMS regional offices; and opportunities for further education for community partners, such as special needs shelters. A ninth team, the Pandemic Preparedness Response Team, was established, whose goal is to develop and disseminate plans to help the kidney community maintain its ability to care for patients in the event of pandemic flu. One major challenge in the ESRD population with pandemic flu is that patients who depend on in-center hemodialysis cannot just stay home. The Pandemic Preparedness Team will work with federal, state and local agencies to assure coordination with KCER planning. The Summit ended with a roll-out of the new Web site (**www.KCERCoalition.com**), which has KCER emergency contact information and links to key resources and organizations involved in preparedness and response for the kidney community. Activities of the 9 response teams are posted on the Web site. Briefly, the response team focus areas are:

- patient assistance: education of patients on preparedness and coordination of financial aid when needed and available
- communication: toll-free helpline, e-mail listserv and conference calls during emergencies
- facility and patient tracking: tracking of displaced patients and reporting on facility open/closed status
- federal response: education of federal agencies and state partners and direct federal resources during a disaster response
- staff and volunteers coordination: maintenance of a database of emergency/disaster volunteers and education on deployment
- industry supplies and services: assistance with plans for emergency distribution of dialysis and transplant supplies
- physician placement and assistance: facilitation of the provision of nephrology expertise for management of dialysis and transplant patients during a large-scale crisis
- pandemic preparedness: collaborate with federal/state agencies to coordinate ESRD services in the event of a major pandemic
- facility operations: assistance of facilities with preparedness and response

THE SOCIAL WORKER'S ROLE IN PLANNING, RESPONSE AND IMPROVING OUTCOMES

Medicare ESRD Conditions for Coverage require that social services are provided to patients and their families and are directed at supporting and maximizing the social functioning and adjustment of the patient. This includes: conducting psychosocial evaluations; participating in team review of patient progress and recommending changes in treatment based on the patient's current psychosocial needs; providing casework and group work services to patients and their families in dealing with the special problems associated with ESRD; and identifying community social agencies and other resources and assisting patients/families in their utilization of them. Social workers have the opportunity in their role to significantly impact patient and family emergency preparedness. Medicare regulations require facilities to have written disaster policies and procedures in place, train all personnel in their roles in emergencies and fully inform patients regarding where to go, what to do and who to contact. Social workers are required to assist at the provider level by knowing and following the facility's emergency preparedness policies and procedures. Social workers can provide support to patients and their loved ones in their emotional adjustment to emergency events. Identification of community social agencies/resources and education are important components to being prepared, not just when emergencies occur, but throughout the year. Emphasis should be placed on year-round preparedness education. An important component of this education is to empower patients to know their plan. Ask patients specific questions about their plan, such as how they will communicate or what is their back-up plan for transportation. Advise that dialysis services may not be available for days when emergencies occur, so patients should have their current flow sheets, treatment orders, emergency diet instructions, communication plan and lists of facilities and emergency contacts on hand. Assistance should be offered to patients and their loved ones with resource utilization.

Emergencies can happen with little or no notice, and each partner from the kidney community plays a critical role in the event of a disaster. The work of the KCER requires a coordinated, comprehensive and continuous effort from the entire renal community, not just the coalition. In addition to assisting patients and their loved ones, social workers can:

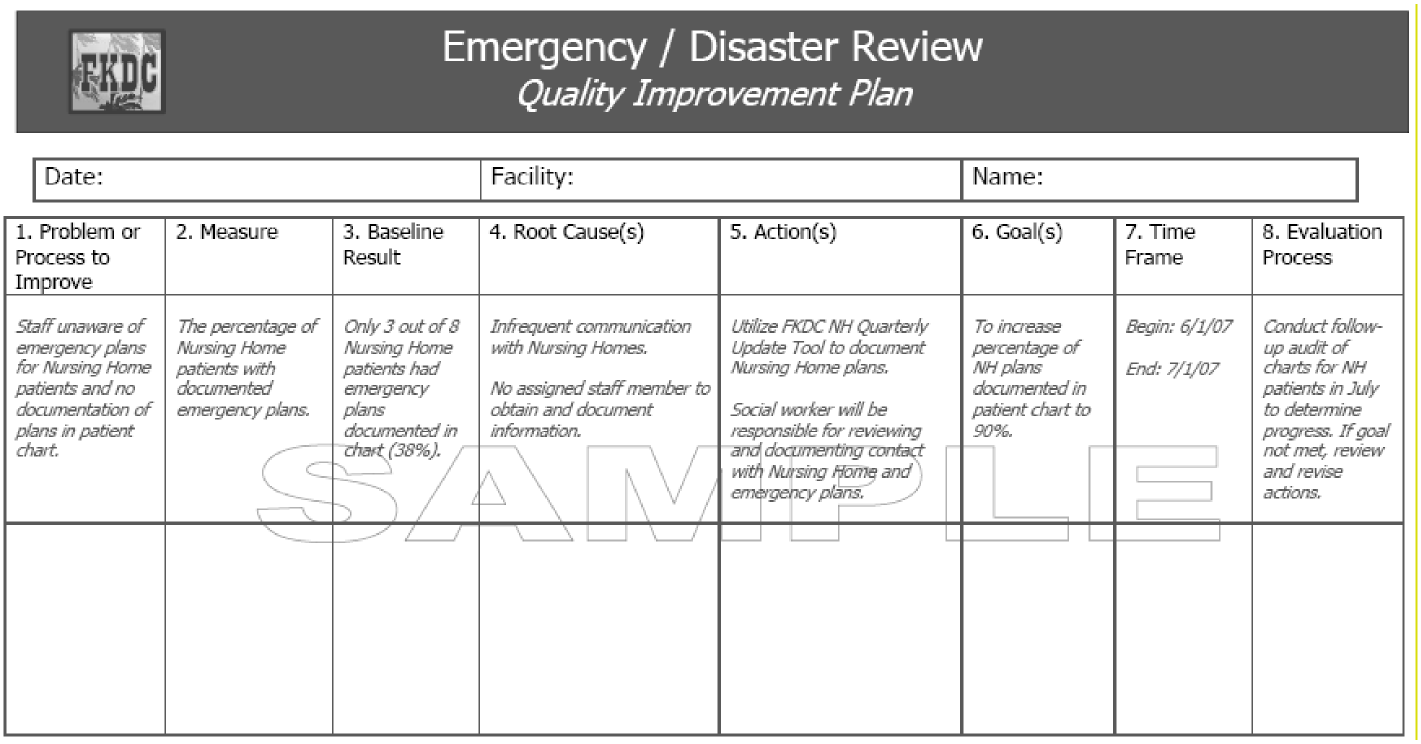
- work within the local community to coordinate planning, including local ESRD Networks, emergency management offices, hospitals and other key responders
- participate in local, state and national coalitions and assist with ongoing coalition development
- assist staff with developing a personal disaster plan
- emphasize year-round preparedness and an all-hazards approach
- conduct practice drills with patients and staff
- continually critique processes.

Social workers should be committed to continued examination of their facility's preparedness level and in improving disaster response performance. With each emergency situation, learning occurs quickly and can be applied to the next event. Conduct continuous quality improvement activities after emergency events to identify lessons learned and improvement opportunities. These efforts can improve quality care and access to treatment for the kidney community, especially during emergencies.

SAMPLE QUALITY IMPROVEMENT PLAN (QIP)

The Florida Kidney Disaster Coalition developed an Emergency/Disaster Review QIP, which can be used to conduct facility in-services or presented or reviewed at monthly quality meetings. Using this tool is an excellent way to demonstrate to Medicare and state survey agencies that a facility is addressing disaster preparedness. The QIP template can be used to review and track improvement in processes based on identified areas of need. Most concerns or challenges faced in disaster preparedness and response can be tracked and measured at the facility level. A sample QIP that addresses the critical role of the renal social worker in the coordination of care in emergency planning for nursing home patients is provided for reference (see Appendix A). A link to download this tool, as well as other resources developed by the KCER, ESRD Networks and their local coalitions is available at **www.KCERCoalition.com** JNSW

APPENDIX A



Emergency / Disaster Review

Quality Improvement Plan

Date:	Facility:	Name:

1. Problem or Process to Improve	2. Measure	3. Baseline Result	4. Root Cause(s)	5. Action(s)	6. Goal(s)	7. Time Frame	8. Evaluation Process
Staff unaware of emergency plans for Nursing Home patients and no documentation of plans in patient chart.	*The percentage of Nursing Home patients with documented emergency plans.*	*Only 3 out of 8 Nursing Home patients had emergency plans documented in chart (38%).*	*Infrequent communication with Nursing Homes.* *No assigned staff member to obtain and document information.*	*Utilize FKDC NH Quarterly Update Tool to document Nursing Home plans.* *Social worker will be responsible for reviewing and documenting contact with Nursing Home and emergency plans.*	*To increase percentage of NH plans documented in patient chart to 90%.*	*Begin: 6/1/07* *End: 7/1/07*	*Conduct follow-up audit of charts for NH patients in July to determine progress. If goal not met, review and revise actions.*

BOOK REVIEW:

Handbook of Health Social Work, Edited by Gehlert, S. and Arthur-Browne, T.
(John Wiley & Sons, Hoboken, NJ, 2006) ISBN: 978-0-471-7143-6. U.S. $80.00

Reviewed by Wayne Walter, MSW
Renal Social Worker

Presumably, most readers of this review practice social work in a health care environment. For such practitioners, a review of their background in social work theory and practice can represent a healthy and revitalizing retreat. *Handbook of Health Social Work* is a textbook for graduate students in social work, but could also be a resource for anyone practicing in the wide spectrum of today's health care. As Jay Cayner mentions in the foreword, "Specific skill sets in team development, communication, data management, negotiation, problem solving, and biopsychosocial interviewing and interventions are presented."

Predictably, this handbook begins with a chapter entitled "Foundations of Social Work in Health Care." Written by the first editor, Sarah Gehlert, PhD, it focuses on conceptual underpinnings of social work in health care. Although it may seem fundamental for those in working in a practice settings, it is always important to be aware of the foundation on which one's practice stands, and the principles of the model being followed. A frequently mentioned topic in the Conference of Nephrology Social Workers' (CNSW) listserv is ethical procedure. The chapter by Jared Sparks, DCSW, focusing on current ethical issues and decision-making is in the foundations section of this handbook. Explanations of commercial insurance, Medicare and Medicaid are briefly presented in the "Health Policy and Social Work" chapter, and there is also a discussion of current efforts to reform these resources to make them more useful.

Issues that social workers in health care face daily are the subject of the second section titled "Health Social Work Practice." A long chapter contributed by M. Engstrom, PhD, explains interaction, assessment and interventions at the crossroads of physical and mental health. There is a chapter by Kevin Burke, PhD, entitled "Religion, Spirituality, and Health" that can help social workers to distinguish the concepts, and use the strength of a healthy spirituality during times of crisis. Chapters on families affected by illness, and sexuality and intimacy, help a health care social worker understand the dynamics of health issues within the family system. The chapter entitled "Substance Abuse Problems in Health Social Work Practice" is especially helpful when this issue is part of the situation to be addressed.

"Selected Areas of Practice" is the title of the third section of the handbook. This section includes a chapter of utmost interest to this journal's audience: "Nephrology Social Work." In it, Teri Arthur Browne, MSW, LSW, co-editor of the handbook, describes end-stage renal disease (ESRD) as it relates to the patient and family system, the experience of uremia and each modality's treatment regimen; the chapter goes on to discuss its impact on the public health, Medicare and commercial insurance resources. Complex psychosocial aspects are also described. Then the role of social worker in the chronic care setting is discussed, including assessment, counseling/education, crisis intervention, rehabilitation guidance, end-of-life care and case management. The social worker's role as member of the care team and patient advocate is also focused on. Everyone practicing nephrology social work, including this author, is painfully aware of the multitude of clerical tasks that complicate its practice. Ms. Arthur-Browne addresses this topic, too, and includes findings from research conducted mainly by nephrology social workers. Finally, this author describes CNSW and ESRD Network resources.

This chapter could perhaps be a good teaching tool for corporate and local clinic administrators who are educated as physicians, nurses or business managers. The text explains the nephrology social work specialization and helps clarify the role for the social worker who feels overwhelmed by the variety of tasks that always seem to demand immediate attention.

The broad scope of *Handbook of Health Social Work* might possibly make the book more comprehensive than any one social worker wants or needs, but its comprehensive nature makes it a valuable resource that should not be overlooked. As a nephrology social worker, I can attest that at least 15 of the 22 chapters in this handbook address issues encountered in any nephrology social worker's practice. Money spent on this textbook would not be spent poorly. Be prepared to spend time studying, and come to appreciate the resource it is meant to be. JNSW