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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.

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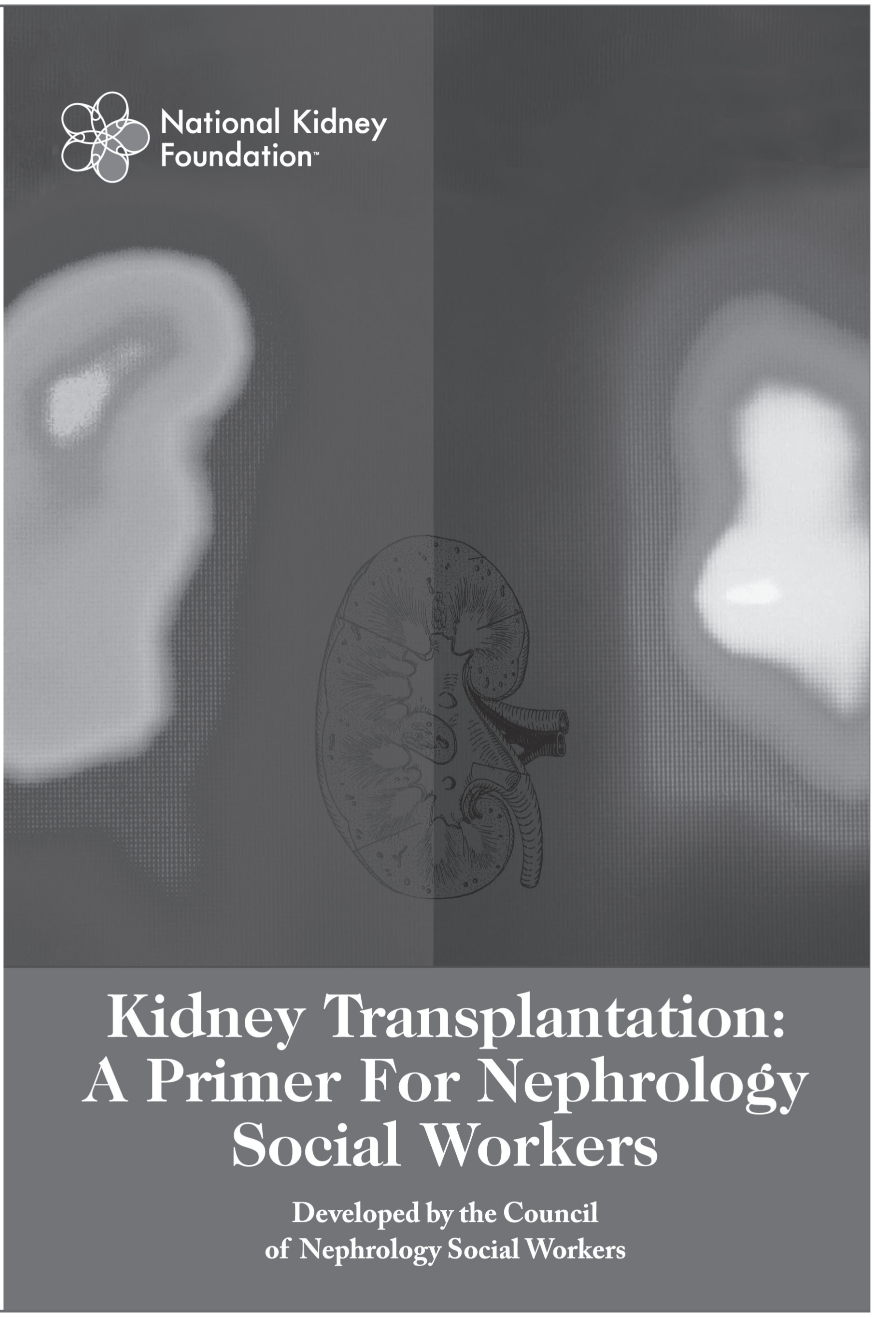

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The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The next issue of the journal will contain articles addressing contemporary issues/topics relevant to nephrology social work. Authors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

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- Kidney Transplant
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- End-of-Life Concerns
- Sleep Disorders
- Sexual Functioning
- Aging and Gerontological Issues
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- Comorbid Illnesses
- Home Dialysis Modalities
- Professional Roles
- Rehabilitation
- HIV/AIDS
- Quality of Life
- Ethics

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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.

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Order of the Manuscript Sections

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

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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.

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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.

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THE JOURNAL OF
NEPHROLOGY SOCIAL WORK

Volume 26
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CONTENTS

A MESSAGE FROM THE GUEST EDITORS FOR THIS ISSUE

As Guest Editors for this one time special issue of the *Journal of Nephrology Social Work*, we are pleased to present "Findings from the Dialysis Outcomes and Practice Patterns Study (DOPPS) and Their Implications for Nephrology Social Work Practice." DOPPS, described in detail in the following articles, is an observational, longitudinal study providing a wide range of data on a sample of people on hemodialysis randomly selected from nationally representative samples of dialysis facilities in 12 countries. The goal of DOPPS, which was initiated in 1996 and is currently ongoing, is to examine various practice patterns in the treatment of people on hemodialysis and their impact on outcomes of care, including morbidity, mortality, hospitalizations, and quality of life. Although observational in design, DOPPS findings provide an important level of evidence supporting health professional practices associated with improved patient outcomes.

Although most, if not all, DOPPS findings are of interest to nephrology social workers, specific findings are of particular importance. The following articles focus on a number of issues and targeted populations—adherence, depression, people with diabetes, elderly persons, quality of life, and withdrawal from treatment. Each article provides relevant DOPPS data and then explores social work interventions designed to improve patients' quality-of-life outcomes.

We hope that as nephrology social workers you find the material presented a valuable addition to your knowledge base and that the interventions presented will offer strategies and techniques to enhance your social work practice.

Pat McKevitt, ACSW, LCSW
DOPPS Advisory Board

Donna Mapes, DNSc, MS, RN
Senior Researcher, DOPPS

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Designing Nephrology Social Work Interventions to Improve Self-Management and Adherence Based on the Dialysis Outcomes and Practice Patterns Study

Mary Beth Callahan, ACSW/LCSW, Dallas Transplant Institute, Dallas, TX

Along with other studies, the Dialysis Outcomes and Practice Patterns Study demonstrates that adherence to treatment has been shown to impact morbidity and mortality for people with chronic kidney disease. Dialysis treatment teams continue to seek ways to help patients understand the short- and long-term effects of nonadherence to medical recommendations. This article highlights nephrology social work interventions designed to improve patient self-management skills through cognitive behavioral techniques.

INTRODUCTION

Patient survival in Europe and Japan is better than the United States even after adjustments for age, gender, and diabetes (Saran et al., 2003). A detailed examination of practice patterns was undertaken in the Dialysis Outcomes and Practice Pattern Study (DOPPS) to try to understand this and many other questions regarding care outcomes. DOPPS I, an ongoing international, observational, and prospective hemodialysis study, was initiated in 1996. Countries included in this phase of the study include Japan, the United States, France, Germany, Italy, Spain, and the United Kingdom.

Nonadherence is a determinant of treatment outcomes including endpoint outcomes of morbidity and mortality. DOPPS data shows that skipping one dialysis treatment a month can increase mortality by 30% (Saran et al., 2003). Other research has shown similar trends (Leggett et al., 1998; Kimmel et al., 1995). Skipping dialysis once a month also leads to a 16% higher risk of hospitalization than for patients who did not skip (Saran et al., 2003). Prior to DOPPS, the risk of hospitalization associated with nonadherence had not been reviewed closely despite its effect on cost containment and patient morbidity.

Patient level predictors of nonadherence in DOPPS included younger age, female gender, African American race, employed status, living alone, smoking status, depression, marital status, and time on end-stage renal disease treatment. These predictors were associated with varying nonadherent behaviors including skipping and/or shortening treatment, weight gain between treatment, hyperphosphatemia, and hyperkalemia. Additionally, a high correlation was found among different measurements of nonadherence. In other words, when one measure of nonadherence was present, there was a statistically significant chance that other nonadherent behaviors would be found. The highest correlation was seen between shortening and skipping hemodialysis treatment (Saran et al., 2003). Larger facility size was associated with a higher probability of patients skipping treatment.

An important focus of nonadherence is large interdialytic weight gains, which can have an adverse impact on blood pressure, which in turn leads to increased cardiovascular risk (National Kidney Foundation/KDOQI Workgroup, 2005). Challenges to adherence include disease factors, treatment regime, and individual/family context (Linsk & Bonk, 2000). Determinants of successful adherence include access to resources and medications, social support, and adherence techniques such as increasing the capability of a patient and ensuring that patients understand the implications of nonadherence (Gallegos & Giddens, 2004).

The thought-provoking question is: How can social workers provide interventions that impact treatment outcomes in a time-efficient, effective manner?

NEPHROLOGY SOCIAL WORK INTERVENTION STRATEGIES TO IMPROVE ADHERENCE

Targeted psychosocial interventions provided by nephrology social workers who are part of the interdisciplinary team working with dialysis patients can improve outcomes by improving patient self-management (adherence to medical recommendations). The nephrology social worker's training in systems theory aids in the assessment of modifiable health risk behaviors. These health risk behaviors in dialysis patients include:

- treatment adherence (missed and shortened treatments)
- fluid adherence (interdialytic weight gains)
- dietary adherence (low salt, phosphorous, potassium, sugar)
- medication adherence
- lifestyle behaviors (smoking, exercise)
- social support
- depression management
- affect (stress and anger) management

As outlined in the CNSW “Outcomes Driven Model of Nephrology Social Work Practice” (National Kidney Foundation [NKF]/Council of Nephrology Social Workers [CNSW], 2006), social workers focus on four tenants that support adherence behavior: knowledge, resources, motivation, and life skills. Social workers must continually assess these four areas to understand the needs and strengths of the patient and achieve success.

Social workers are taught early in their graduate education to “begin where the client is.” Patients’ readiness to manage their disease is impacted by their phase of adjustment to chronic kidney disease, which can be divided into three phases (NKF/CNSW, 2006; Figure 1):

- Phase I: Diagnosis and/or initiation of renal replacement therapy
- Phase II: Chronic fluctuating illness
- Phase III: Physical decline/death

Patients may not be ready to struggle with adherence if it has only been 1 week since they learned that without dialysis they would no longer be able to live. Focused psychosocial assessment and intervention are key to facilitating improved understanding and adaptation to illness. To promote an effective intervention design that targets the identified health risk behavior, social workers must understand where the patient is in his or her adaptation to illness, what the patient gains if medical recommendations aren’t followed, and what is given up if recommendations are followed. This gain and loss paradigm extends to the patient’s support system. Adherence, therefore, is a lifelong management task that promotes wellness and survival by managing behaviors and risks that are impacted by psychosocial variables across the lifetime of patients and their support systems.

Figure 1

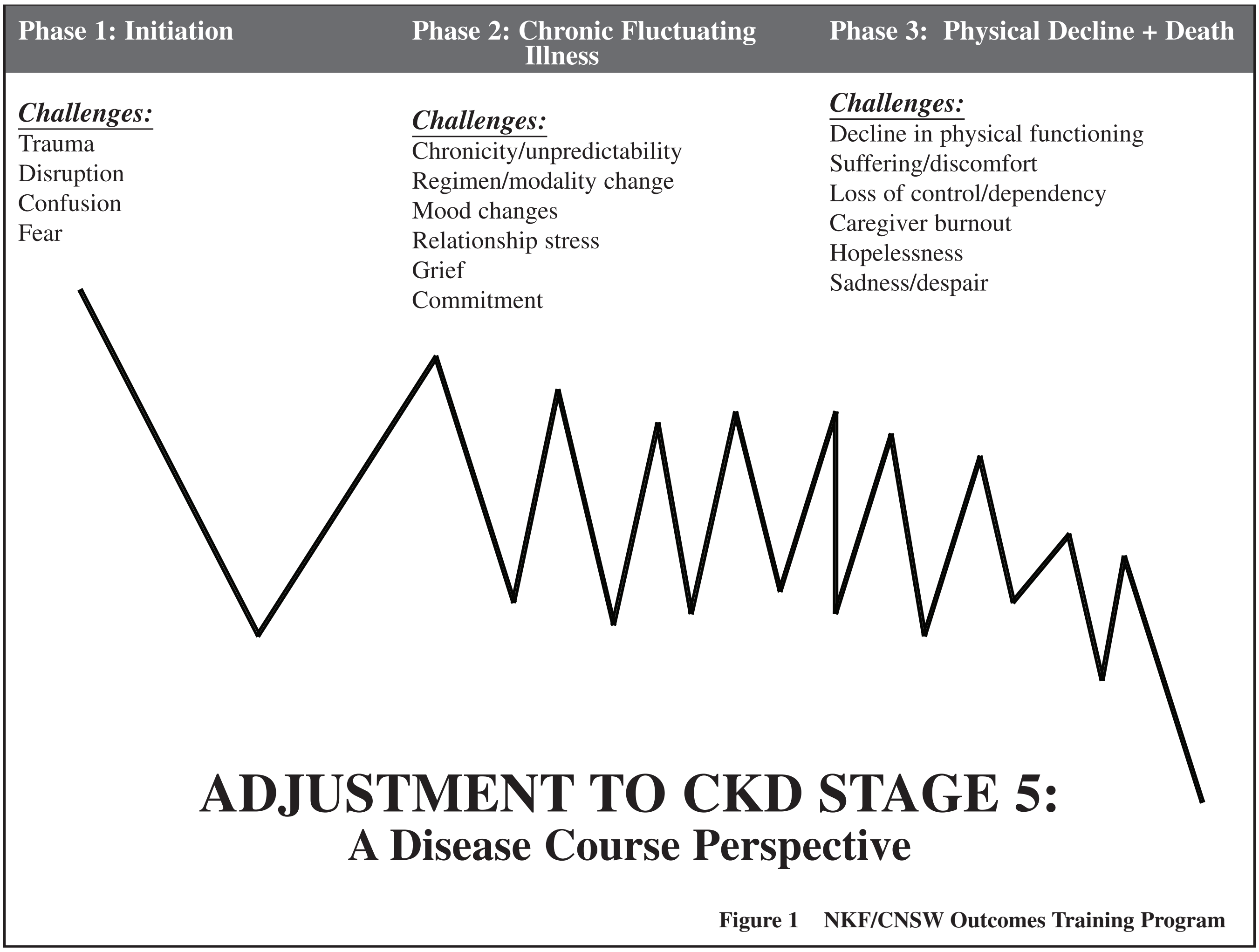


Figure 1 NKF/CNSW Outcomes Training Program

THE ADHERE MODEL AND NEPHROLOGY SOCIAL WORK INTERVENTION

ADHERE is an acronym for a model developed by Gallegos et al. (2004) that offers strategies to improve self-management success. Key words in this paradigm, which are discussed further in the following sections, are *assess, dialog, holistic, empower, reinforce*, and *evaluate*. Incorporating this approach in social work intervention promotes patient adherence.

Assessment is ongoing and essential to targeting interventions for patients. The Life Options Rehabilitation Advisory Council (LORAC) developed patient interest checklists that can be given to patients to ascertain their level of understanding on various aspects of kidney disease and treatment for different time spans during their adaptation process. In addition, LORAC offers fact sheets to help teach many of the topics patients are interested in learning (Life Options, 2006). For social workers wishing to develop their own surveys, an adherence assessment checklist might ask the following:

1. What do you know about dialysis? Fluid gains? Blood pressure control, etc.?
2. Who is part of your support system?
3. From where do you draw your personal strength?
4. What do you feel is the most challenging aspect of limiting your fluids?
   a. taking your phosphorus binders?
   b. coming to all of your dialysis treatments?
   c. staying for the full treatment, etc.?
5. What are your short- and long-term goals for treatment?

By identifying and prioritizing adherence problems in their dialysis populations, social workers become an integral part of continuous quality improvement and are able to determine appropriate questions for goal setting

Figure 2

Fitting Treatment Into Your Lifestyle

• My eating habits	When and how many times a day you eat?
• My sleeping patterns	When and how well to you sleep?
• My regular exercise	Walking, aerobics, dancing, weights, cleaning house, gardening.
• My social supports	Family, friends, spiritual organization, support group, dialysis center.
• My work/financial situation	Will my job be flexible with my hours, is home dialysis a choice, should I file for SSDI to have a steady income?

Adapted from AIDS Action Committee, MA 2003

and targeted interventions. Prioritizing issues and the need for intervention may come from awareness of a trend in the clinic setting, industry standards, or corporate needs/requests.

Using the ADHERE model, assessing patients' knowledge and readiness for change moves social workers into a dialog with patients about their health beliefs and options. Dialog in the ADHERE model helps to clarify the possible consequences of nonadherence and reviews self-care strategies. Through this dialog, which may include motivational interviewing, social workers come to understand what gains and losses the patient perceives through adherence to medical recommendations.

A holistic approach includes looking at a patient's environment, culture, resources (internal and external), and support system to promote the best treatment outcome. "Fitting Treatment Into Our Lifestyle: A Worksheet" was developed by the AIDS Action Committee (Gallegos et al., 2004) as part of the ADHERE model. This worksheet was easily adapted for patients with kidney failure (see Figure 2). Taking a holistic approach allows a review of the person-in-environment fit and targeting of social work interventions as indicated to improve treatment outcomes.

Nephrology social workers empower patients by encouraging them to be active participants in disease management and treatment. Using the strengths perspective and motivational interviewing in teaching may increase the likelihood that patients will more effectively manage or adhere to medical recommendations. The strengths perspective focuses on the dignity of every human being and builds on people's strengths and capacities rather than focusing on their deficits, disabilities, or problems. Emphasis is placed on uncovering, reaffirming, and enhancing the abilities, interests, knowledge, resources, aspirations, and hopes of individuals, families, groups, and communities (Saleebey, 1996). Motivational interviewing is a patient-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence. It seeks to help create a collaborative relationship within which social workers can skillfully use directive listening techniques to address patient reluctance to change and to determine the patient's personal motivations to initiate and persist with behavior change (Miller & Rollnick, 2002; Rose, 2006).

Social workers can enhance interventions focused on improving adherence by reviewing Prochaska et al.'s six-stage process in their book *Changing for Good: A Revolutionary Six-Stage Program for Overcoming Bad Habits and Moving Your Life Positively Forward* (1994). The six stages are:

1. precontemplation
2. contemplation
3. preparation
4. action
5. maintenance
6. relapse or recurrence of target behavior

As social workers understand a patient's readiness to contemplate change, interventions can be more effectively shaped to the needs of the patient and reinforced. An example of this might be blood pressure management, which in patient John Brown's case, demonstrates that his blood pressure is totally out of control. The team is focused on instructing him to take his medications. Mr. Brown does not understand why this is such a big problem. He knew it was important to try to keep his blood pressure down before dialysis, but now that he's started dialysis, his kidneys are gone and he thinks "What's the use?" As a social worker, it is important to understand what Mr. Brown gains by not taking the medications—better sexual function, fewer dollars spent, increased control or fewer demands because he's not having to take medication. It is also important to understand what he might not like about needing antihypertensive medications—the staff nagging him, headaches, etc. At this point, Mr. Brown does not understand the long-term health complications related to uncontrolled blood pressure, such as stroke.

As Mr. Brown's readiness for change is assessed, it is important to understand what he might lose by starting to take blood pressure medications. This could be money and/or sexual relationships, which in turn might lead to loss of self-esteem, depression, etc. It also needs to be determined if Mr. Brown can identify anything good about starting to take his blood pressure medications. As his ambivalence to change is assessed using the diagram in Figure 3, he may increase his awareness in a number of areas, including his understanding of the risks associated with his behavior and the positives associated with a potential change. As a professional, the social worker will become better able to target an effective intervention because his resistance to change is understood. Through use of the Prochaska model, teaching can be reinforced throughout the process but teaching is approached knowing that there will likely be relapses during any stage or all stages of the process (Figure 4). Knowing that relapses are a possibility allows the social worker to proactively plan to continually reinforce changes in behavior.

Figure 3

Am I Ready for Change?

Adapted from Gary Rose, PhD, "Motivational Interviewing." NKF 2001 Spring Clinical Meetings, NKF/CNSW Outcomes Training Program

What I like about fluid is:

- It makes me feel better right away.
- Easier

If I changed, the good thing might be:

- I would have easier tx.s.
- Feel better about myself.

"Ambivalence"

What I don't like is:

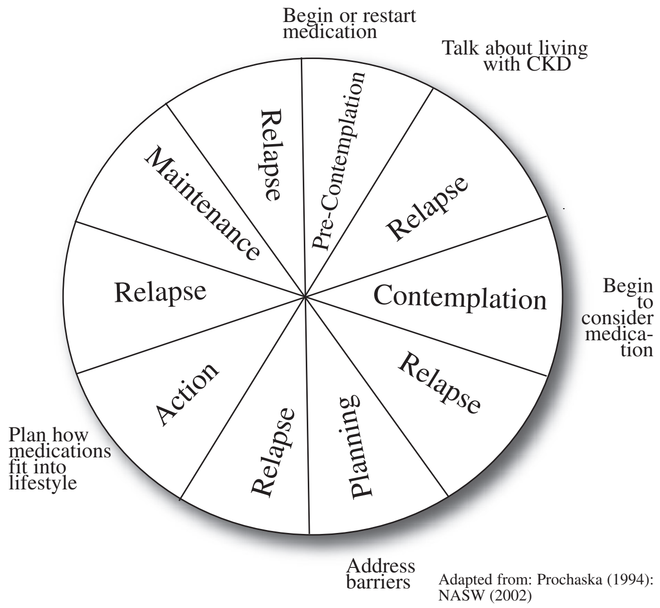
- Doctor/nurses lecture me.
- Shortness of breath/ cramps
- I feel ashamed

What I might lose by giving it up is:

- Less feeling of control
- Less social freedom
- Comfort (I might be very thirsty.)

Figure 4

Stages of Change Behavior



Adapted from: Prochaska (1994): NASW (2002)

Fluid management is often a significant challenge for people on dialysis and is an issue that lends itself to a group approach. An example of a three-session class based on cognitive behavioral, motivational, and paradoxical interventions is as follows (Johnstone, 2003):

Class 1:

- The story of Joe (someone with a fluid problem)
- Why the nurses get so upset (the risk of cardiovascular disease to the patient)
- Feeling "bad" is not good for you!
- Reframe: struggling and learning
- The decisional matrix (refer to Figure 3)
- Look at the fluid tracker (Figure 5), but don't make any changes

Figure 5

30-DAY
"Fluid Tracker"

DIRECTIONS: Measure the fluids you use every day.

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Week 1							
Week 2							
Week 3							
Week 4							

Taken from CNSW Research Project: Living Longer, Living Better, 2001. (Johnstone & Callahan)

Class 2:

- Cycle of a craving
- Craving control toolbox
- Continue fluid tracking

Class 3:

- Results of playful experimentation with tool box
- Fluid control journey is forever
- Preparing for and responding to relapse
- Review of class
- Readiness to set small goals

Finally, social workers need to continuously monitor intervention outcomes by evaluation as noted in the ADHERE model. Outcomes can be measured in a myriad of ways, which include treatment records, lab reports, surveys, scaling by patient, quality-of-life measurements, and pill counts. Evaluating outcomes is often difficult for social workers because of high caseloads, inexperience with evaluation, etc. However, evaluating interventions does not have to be formal. It can be as basic as asking Mr. Brown if he perceives a difference in his day-to-day activities since he decided to try to take his medications for a period of 4 weeks. If there is no follow-up and measurement of the outcome, improvement in adherence cannot be determined. If follow-up and reporting outcomes are recorded in progress notes, care plans, even perhaps as a small continuous quality improvement project, it becomes a part of everyday practice—something that becomes easier to do each week.

Focusing on improving adherence may seem a daunting task. However, the key is to start small. Identify two patients with similar adherence issues, plan a 10-minute intervention, deliver the intervention, and measure the outcome.

SOCIAL WORK INTERVENTIONS WITH STAFF REGARDING ADHERENCE

Struggling with patient nonadherence to medical recommendations is often very difficult for dialysis treatment staff as well. Social workers can assist with the team's reaction to nonadherence and help support management in shaping the culture of the setting. The focus with staff is to help them identify how they feel and why they feel as they do when Ms. Green comes in with an excessive interdialytic weight gain. Is the staff concerned that Ms. Green may die if she continues excessive weight gains? It may be helpful to have short (10-minute) sessions with staff to discuss "if/then" and help them sort out their reactions in a non-stressful environment. The fear is often, "What if she dies?" It can also be helpful to think through transactional analysis concepts with the staff (parent/child, child/child, adult/adult) and how this might be impacting their communication with patients and affecting the outcome of self-management. Are staff members talking to patients as if they were children or with dignity and respect as adults? Rehearsals are fun and can be a great source of learning if time allows.

Social workers can also improve adherence by helping the staff understand changes in contemporary treatment of health risk behavior, such as:

- focusing on patient strengths
- remaining in patient-centered treatment
- shifting away from labeling
- forming partnerships for change
- using empathy rather than authority and power
- focusing on stage-specific interventions, such as the Prochaska Model, that help the patient progress to greater self-management (U.S. Department of Health and Human Services, 1999)

CONCLUSION

When planning targeted social work interventions to improve self-management and adherence or teaching staff to understand change, remember that change is a process. Other key points are:

- Motivation is a continuum of "readiness to change."
- Change occurs naturally.
- Change occurs in steps or stages and occurs over time.
- Patients move back and forth and cycle between stages of change.

Cognitive-behavioral interventions targeted to improve adherence and help patients become more capable of change, focus on their strengths, and make them feel empowered. Focused nephrology social work interventions make a powerful impact on the health and well-being of patients with CKD. Start small, but start!

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Depression Management for Hemodialysis Patients: Using DOPPS Data to Further Guide Nephrology Social Work Intervention

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The future of disease management for the chronic kidney disease population will need to focus beyond the physiological markers of dialysis adequacy, albumin, and blood pressure and include psychosocial and behavioral health variables that also mediate treatment outcomes. A growing body of literature, including the Dialysis Outcomes and Practice Patterns Study (DOPPS), has linked depression to survival and health care utilization in people on hemodialysis. DOPPS identified the need for improved identification and management of depression. It also provides further guidance for nephrology social workers, who will continue to serve as the lead mental health providers to this at-risk population. This article reviews this literature and proposes practice guidelines for nephrology social workers to help manage depression in the dialysis clinic setting.

INTRODUCTION

The future of disease management for the chronic kidney disease population will require that nephrology teams focus on the psychosocial and behavioral health variables that mediate treatment outcomes as well as physiological markers of dialysis adequacy, albumin, and blood pressure. Kidney disease management is likely to follow the trends of cancer, AIDS, and cardiac medicine to develop integrated care models, which have improved survival and quality of life for individuals living with chronic medical illness (Blount, 1998; Herrman et al., 2002; Koopman et al., 1998; Markowitz et al., 1998; Musselman et al., 1998). Depression management strategies for people on hemodialysis will be key to these future disease management models. A growing body of research has linked depression to survival and health care utilization in this population. The Dialysis Outcomes and Practice Patterns Study (DOPPS), an ongoing study of people on hemodialysis in 12 countries that focuses on dialysis practices that contribute to improved outcomes, published research findings suggesting the need for improved identification and management of depression in this patient population (Lopes et al., 2002; Lopes et al., 2004). DOPPS provides further guidance to nephrology social workers, who will continue to serve as the lead mental health providers to this at-risk population.

Nephrology social workers are prepared for these disease management models. In 2007, the National Kidney Foundation (NKF) Council of Nephrology Social Workers (CNSW) Outcomes Training Program (OTP) celebrated its 10th anniversary (National Kidney Foundation, 1996). This program continues to launch Internet- and video-based trainings to help nephrology social workers fine-tune their disease management skills, which are a natural spin-off from their master's-level training in clinical social work treatment and bio-psycho-social case management. The field now has state-of-the-art, brief interventions it can rely on to improve the psychosocial and behavioral health of people on hemodialysis. Among these social work interventions, those that prevent and manage depression are receiving much attention in some dialysis clinic continuous quality improvement (CQI) forums (Johnstone, 2005). The impact of depression on missed treatments, excess fluid gains, patient–provider conflict, and low quality-of-life scores of people on hemodialysis has been observed by social workers for years. The CNSW OTP entitled "Interventions that Identify and Reduce Depression" guides the nephrology social worker in managing depression to reduce these outcome barriers. The OTP program has also been the catalyst for the NKF/CNSW depression management programs. "Feeling Better Again," one of the cognitive-behavioral programs for depression (funded by a NKF/CNSW research grant), was tested in a Florida dialysis clinic. The study, led by Jessica Cabness, PhD, demonstrated improved mood, social support, and overall health quality when on-site depression programming was provided by the dialysis team social worker (Cabness et al., 2006). Another CNSW depression management series program was included in the "People Like Us: Stepping Back Into Life" program, which was released in October 2006 to Hurricane Katrina survivors on dialysis in Louisiana (Medical News Today, 2006).

DOPPS suggests that the CNSW is right on track. Prior

Please note that any comments made or opinions expressed are the author's own and do not necessarily reflect those of, nor are they necessarily endorsed by, her employer Fresenius Medical Care.

to DOPPS' release of data on depression, a steady stream of literature drew attention to the role of depression and its association with treatment outcomes for people on dialysis. This volume of evidence focused on different variables to examine how depression impacted treatment outcomes. Burton et al. was one of the first to link depression to survival in people on hemodialysis (Burton et. al., 1986). Sacks et al. linked depression to perception of illness in people with end-stage renal disease (Sacks et. al., 1990). DeOreo established links between hospital days and mental health scores on the SF-36 quality-of-life instrument (DeOreo et al., 1997). Kimmel et al. established an association between higher levels of depression and mortality that is on the same magnitude as medical risk factors (Kimmel et al., 2000). Curtin examined the relationship between depression and symptom reporting (Curtin et al., 2002). These investigators, among others, illuminated the association of depression with dialysis treatment outcomes. DOPPS provided the opportunity to explore depression on an international level.

In 2002, data was published from the first phase of DOPPS that examined depression as a predictor of mortality and hospitalization (Lopes et al., 2002). Data was analyzed from a random sample of 243 facilities (5,256 patients) across the United States and 5 European countries. The diagnosis of depression was abstracted from both physician diagnosis (from medical records) and two patient self-report questions (Table 1). The finding on international prevalence of depression in this study was nearly 20% and there were links established between depression, mortality, and hospitalization. After adjusting for time on dialysis, age, race, socioeconomic status, comorbidity, and country, the relative risk of mortality with physician-diagnosed depression was 1.23 (which indicates a 23% increase in the relative risk of death). For patients identified as depressed based on the self-report items, the relative risk of mortality was 1.35 for the question "downhearted and blue" and 1.48 for the question "so down in the dumps." With regard to the relative risk of hospitalization, the results were 1.11, 1.11, and 1.15, respectively. The results were similar for U.S. and European patients on hemodialysis. These associations were statistically significant.

Table 1

Two-Item Depression Self-Screener Used in DOPPS[a]

1. "Have you felt downhearted and blue?"
2. "Have you felt so down in the dumps that nothing could cheer you up?"

Possible answers[b]:

none of the time
little of the time
some of the time
a good bit of the time
most of the time
all the time

[a] Questions taken from SF-36.

[b] Bold scores were considered indicative of depression.

In examining some of the correlates of depression in DOPPS I, the data identified that depressed patients were more likely to be unmarried, white, female, age 60 or older, unemployed, to have lower serum albumins, to have been on dialysis for more than 1 year and to suffer from more medical comorbidities (including coronary artery disease, congestive heart failure, diabetes mellitus, peripheral vascular disease, gastrointestinal bleeding, cancer, lung disease, and other cardiac and neurological disease states). The patient self-report question "so down in the dumps" was more effective in identifying depression in non-whites (excluding blacks) and in patients with differing degrees of education. In the study, blacks had a lower likelihood of depression compared to whites, as measured by both physician diagnosis and the self-report questions. It is notable that only 13.7% of patients had a positive response to both self-report questions, while 26.8% were positive for at least one self-report indicator of depression. This data demonstrates the value of using both self-report items (especially the "so down in the dumps" question) when screening for depression in people on hemodialysis.

In their summary, the authors point out that depression in people on hemodialysis, despite the growing demonstration of its link to mortality and hospitalization, remains a largely under-recognized and under-treated psychiatric disorder. They call on providers to examine the value of early screening and treatment to improve quality of life and survival in people on hemodialysis worldwide.

Following the release of this data from the DOPPS I, research continued to illuminate the prevalence and impact of depression in the U.S. hemodialysis population. A study by Watnick et al. pointed out that many people on hemodialysis suffer from depression at the start of renal replacement therapy; however, their depression is not identified (2003). Her study also highlighted the lack of medical treatment provided even to patients who were identified as depressed. Guzman and Nicassio focused on the predictors of depression in people on hemodialysis, and found that both negative and positive illness schema were significant in determining whether a person on hemodialysis might suffer from depression (2003). Kimmel and Peterson conducted a review of the literature on depression in ESRD and noted the evidence of both stressors and protective factors in mediating the levels of depression in people with ESRD (2005). They called for well-designed treatment studies and survival analyses in this population using longitudinal techniques. While these and other investigations kept the CNSW's attention on the importance of depression in ESRD outcomes, DOPPS II provided further information.

In 2004, a second article was published on depression using data from DOPPS II (Lopes et al.). This data provided the industry with a look at how the United States and other countries differed in their approach to the identification and treatment of depression in people on dialysis. This study evaluated the impact of both physician-detected depression and detection using a short (10-item) depression screening instrument in people on hemodialysis. It also sought to evaluate patterns of treatment using antidepressant medication in those patients identified as depressed. Finally, the article examined the impact of depression on mortality, hospitalization, and dialysis withdrawal. The study was randomized and focused on 9,382 patients from 12 countries. The Center for Epidemiological Studies Depression Screening Index (CES-D) was used as a screening instrument, with a cutoff value of 10 or higher as a positive depression score.

In this study, the screening instrument was found to be more effective in identifying depression in the people on hemodialysis than physician diagnosis. Depression was under-identified by physicians in all age groups but more so in patients over 63 years, who had a higher prevalence of depression when measured with the CES-D. Other correlates for depression in this study were living alone; single marital status; female sex; less education; comorbidity (especially congestive heart failure, peripheral vascular disease, gastrointestinal bleeding and neurological diseases); and low albumin, hemoglobin, and Kt/V. When the data from DOPPS II was adjusted for several comorbidities, the patients identified as depressed by the CES-D had higher relative risks of death (1.42), hospitalization (1.12), and dialysis withdrawal (1.55). These findings, from the second phase of DOPPS, reinforce those from DOPPS I. Both studies suggest that depression is undetected as well as undertreated in people on hemodialysis worldwide. They also point clearly to the relationship between depression and survival and hospitalization.

Both phases of DOPPS offered additional support to the association of depression to survival and hospitalization through the examination of the data gathered from the KDQOL-SF.™ This quality-of-life instrument measures domains related to mental, emotional, social, and role functioning. These domains, when combined, can be factored into a mental composite score (MCS) that is often tied to survival in people on hemodialysis (DeOreo, 1997). In DOPPS, patients scoring 10 points lower on the MCS had a 13% higher death risk and a 6% higher risk of first hospitalization. DOPPS found that low MCS scores were at least as powerful in independently predicting hospitalization and death as albumin (Mapes et al., 2003).

When looking back at the DOPPS II data for the United States (1,300 patients), physicians detected depression in 21.7% of the patient sample, which was higher than any other country in the study. This may indicate a lesser stigma in the U.S. population regarding depression, and a tendency for providers to accept it as a medical illness. Despite what may be increased levels of comfort with and confidence in physician approach to depression, it is notable that the CES-D screening tool detected depression in nearly twice as many patients (39.2%) in the United States as did physician diagnosis. Though the authors are careful to point out that physician-identified depression may be underreported in this study due to medical record omission, the use of a depression screening tool in people on hemodialysis appears to be important as an adjunct to physician assessment.

With regard to treatment for depression, 38.9% of patients that were identified by U.S. physicians as depressed received antidepressant medication therapy. Of the patients identified as depressed using the CES-D (a much larger group of patients), only 28.9% had been treated with antidepressant medication. The low treatment rate provided to this at-risk population may have had far-reaching effects. When adjusted for age, sex, socioeconomic factors, length of time on dialysis, and country, there was a 55% higher relative rate of withdrawal from dialysis for patients that were identified as depressed by the CES-D.

There was also an independent and significant association with a higher relative risk of dialysis termination for patients who were diagnosed as depressed by their physicians (Lopes et al., 2004). These data suggest that physicians and other members of the dialysis team can play an important role in improving detection of depression and monitoring treatment access, and that those team functions might impact survival through multiple pathways. They also demonstrate how much still needs to be done to ensure that depression is identified and treated in people on hemodialysis in the United States.

Kimmel and Peterson posed this issue as a challenge to the industry in their 2006 editorial entitled "Depression in Patients with End-Stage Renal Disease Treated with Dialysis: Has the Time to Treat Arrived?" This editorial speaks to the strong correlation displayed between depressive symptoms and both death and cardiovascular events in the Choices for Healthy Outcomes in Caring for ESRD (CHOICE) study in that same issue of the *Clinical Journal of the American Society of Nephrology* (Boulware et al., 2006). The study of 917 people on dialysis over a 2-year period highlights the need to treat persistent and current depressive symptoms, which are most strongly associated with poor medical outcomes. On the heels of the DOPPS data, and in light of the ever-growing body of literature demonstrating the risk of *not* treating, the answer to this question posed by Kimmel and Peterson seems to be a resounding "yes."

IMPLICATIONS FOR NEPHROLOGY SOCIAL WORKERS

So, where does that leave nephrology social workers as the lead mental health providers of care for people on hemodialysis? How should the profession respond to this sense of urgency? The CNSW's OTP offers guidance and direction at this most important time. The OTP program entitled "Interventions that Identify and Reduce Depression" points out that successfully managing depression in the hemodialysis population requires focus on four key areas: education, screening, prevention, and response. Each of these areas of focus is discussed later in this article, along with guidelines to direct the nephrology social worker toward effective depression management intervention in the hemodialysis clinic.

Education

Nephrology social workers have been providing psycho-education to people on dialysis since they joined the renal team more than 30 years ago. The task of bio-psycho-social assessment and identifying potential barriers to patient adjustment are fundamental skills of the master's level social worker in the hemodialysis clinic. What is needed, as social workers focus these skills in on depression management, is the addition of a focused, brief time period with all new hemodialysis patients (and possibly their loved ones) to explain the risk for depression as they begin and continue dialysis therapy. This intervention session could include information on self-assessment for depression and the signs and symptoms of depression compared to those of uremia. It could also evaluate a patient's history of depression and other mood disorders, and identify the signs and symptoms related to any previous episode of depression.

The goal of this educational session could be to reduce stigma and to obtain patient buy-in on the impact of depression on quality of life, wellness, and survival. Additional goals would include helping the patient discuss this risk with family and loved ones, and ritualizing those loved ones into ongoing "surveillance" for the signs and symptoms that would warrant further evaluation (Table 2). The patient and loved ones could be taught what the next steps would be if depression were suspected (further screening) and if depression were detected (the safety of contemporary treatment). Distorted and mythical thinking about depression treatment such as "Depression means I am weak," or "If I take medication I won't be myself," could be solicited and countered to reduce avoidance of the problem. The outline provided in Table 3 is designed to guide a nephrology social work session that addresses these important issues.

Table 2

Does Your Loved One Suffer From Depression?

You may be the first to spot depression in your loved one. If your loved one has the signs and symptoms of depression below don't blame it on dialysis. See your social worker or doctor right away! It could be depression.

Some signs and symptoms of depression:

- Feeling down all day, nearly every day, for at least 2 weeks
- Feeling worthless and bad about oneself
- Loss of interest or pleasure in things that used to be pleasurable
- Unexplained changes in mood, including irritability
- Feeling hopeless, not caring anymore, or having thoughts of "giving up"

Table 3

Nephrology Social Work Approach to Education: Risk of Depression

1. Introduce the talk about depression as a serious matter:
   "I have to talk to you briefly about something important: something that could effect how well and long you live."

2. Discuss the following key points:
   a. The prevalence of depression (up to 25% of patients)
   b. The risk if depression goes untreated (a simple review of what studies show)
   c. The benefits of depression prevention and treatment
   d. The safety and efficacy of treatment (explaining medication, psychotherapy, and the value of both)
   e. How to watch for the signs and symptoms of depression (patient and loved ones; ensure comprehension by having patient repeat back)
   f. The role of screening tools and how the hemodialysis facility may utilize them to further watch for depression (encourage patient acceptance and utilization of screening services)

Screening

When using a depression screening tool with people on hemodialysis, there are many factors for nephrology social workers to consider. Some patients in dialysis centers respond to any type of survey with resistance because of the time and effort required of them to participate in it. In addition, some patients have literacy deficits and may state that they are "not interested" or "too tired" rather than discuss their inability to read or write well enough to complete an instrument. Some patients experience such severe neuropathy that they cannot hold a pen long enough to complete an instrument, and do not want to take valuable time from a family member or dialysis team member by asking for assistance. Other patients find surveys an invasion of their privacy. In addition to all these barriers, there is the significant risk of patients experiencing stigma when the topic of depression is discussed.

Prior to launching a depression screening program, it is important for the nephrology social worker to prepare for these multiple barriers, and grow comfortable with the stigma, intimacy, language, and process involved with depression screening. Once the social worker achieves a comfort level with the discussion of depression, he or she is likely to be well received by the patient and supported by other members of the renal team when performing screening interventions in the clinic.

When choosing a screening instrument, a person on hemodialysis may benefit from the choice of a brief and easy-to-understand screener with a 1- to 5-minute administration time (Williams et al., 2002; MaCarthur Initiative). It is possible to use the 2-item screener, abstracted from the KDQOL-SF™ instrument, which was used in DOPPS (Table 1). Another 2-item screener, the PHQ-2, has gained attention in medical settings because, like the questions used in DOPPS, it attends only to non-somatic indicators (anhedonia and dysphoria), which may reduce bias (false-positives) related to the disease (Corson et al., 2004; Kimmel et al., 1993; Kroenke et al., 2003). The National Heart, Lung and Blood Institute Working Group Report identified this instrument as the best screener for patients with cardiovascular disease, which presents in nearly 50% of people with ESRD (Davidson et al., 2006). If the brief questions on these screeners produce a positive score for depression, the nephrology social worker can then move toward further evaluation with a more sensitive screener to determine level of depression in people on hemodialysis. Instruments such as the Beck Depression Inventory, Beck Depression Inventory-Fast Screen for Medical Patients, Cognitive Depression Inventory, PHQ-9, CES-D, and Geriatric Depression Scale are among the more sensitive tools that have been used to assess depression in people on hemodialysis (Beck, 1961; Guzman & Nicassio, 2003; Halverson & Chan, 2004; Kroenke et al., 1999; Radloff, 1977; Sharp & Lipsky, 2002; Yesavage et al., 1983). Kimmel cautions that we need more research in the area of reliable measurement, and suggests that only 5 to 10% of hemodialysis patients may suffer from major depression disorder compared to a larger number that suffer from increased levels of depressive affect. The prevalence of depression is likely to vary between hemodialysis clinics, based on the screening tool chosen.

Despite the choice of screener, it should be noted that patients may require assistance with depression screening due to literacy and concentration problems noted in this population (Kurella et al., 2004). This will ensure that the screener chosen will provide an accurate response. In addition, attention must be given to cultural bias when screening. Kimmel points out the possibility that African Americans, though presumed to have the same prevalence of depression in the general population as others, may under-report depressive symptoms or be inaccurately measured during screening (Kimmel et al., 2002). Discussions with all patients should focus on their comfort with screening activity, and should seek to increase that comfort. Table 4 includes steps that a nephrology social worker might take to implement an effective depression screening program in the dialysis clinic.

Table 4

A Nephrology Social Work Approach to Depression Screening

1. **Decide on frequency and inclusion in the screening process.**
   Patients that screen negative, show good adjustment to illness and have no history of depression may be able to self-screen and/or be screened annually. Others may benefit from more regular screening. Patients beginning any type of treatment for depression would benefit from frequent screening to ensure remission of symptoms.
2. **Collaborate with all attending physicians at the hemodialysis facility to involve them in your screening efforts.**
   Display available screening tools and their scoring protocols to physicians. Provide articles on the risks of depression. Consider a smaller CQI or pilot project to get started with screening. Explore treatment options with all rounding physicians and inquire about their treatment preferences.
3. **Re-educate the patient briefly on the value of depression screening.**
   Focus on the value to their health if depression is identified and treated. Remind them that symptoms of depression are often hidden behind the symptoms of kidney failure, making screening more important. Reassure them that depression is common and, should it be identified, that treatment is safe and effective. Assess for fears or concerns related to the screening process.
4. **Track scores and share comparison scores with patient.**
   Reviewing scores helps patients feel informed and included in the screening process, creating an opening to discuss treatment if needed. It also helps a patient to watch over more subtle changes in mood that might precede an episode of major depression. Identifying smaller mood changes could encourage a problem-solving session with the social worker that might help guard against depression.
5. **If the screening scores do not endorse depression, encourage continued self-screening.**
   Offer tips on how patients can report changes in mood to you or their physician. Thank the patient for allowing you to be a part of this important aspect of their health care.

Prevention

Although more research is needed in the causality area, there is some evidence to guide nephrology social workers when designing interventions to prevent depression. Guzman completed one of the most important studies regarding the predictors of depression among people on hemodialysis. In this study, published in the *Journal of Behavioral Medicine*, Guzman teamed up with a nephrologist to control for medical severity, which helped examine depression without the superimposed symptoms of kidney failure (Guzman & Nicassio, 2003). As a result, several factors were isolated that predicted depression in a person on dialysis. The most significant factors were those related to self-illness schema (both negative and positive schemas were significant), social support (especially in the areas of self-esteem support and belongingness support), body image, and perceived stigma.

The findings from Guzman's study became part of the CNSW OTP and also helped craft the NKF depression management programs. These programs use cognitive, interpersonal, and problem-solving techniques to build internal skills that can help patients guard against depression. This type of brief prevention programming, offered on-site at dialysis clinics, has been shown to improve mood and is likely to reduce depression risk (Johnstone, 2005). This is especially true because patients have been shown to prefer to receive treatment for depression from their nephrology social worker at the dialysis clinic, rather than an outside mental health provider (Roberts et al., 2006). For the smaller group of patients who are willing to pursue a referral to a community provider for depression treatment, barriers to seeking these services outside the clinic are numerous.

When designing an on-site depression prevention program, nephrology social workers might follow the steps displayed in Table 5. This approach to prevention, which focuses on strengthening patient behaviors and skills to reduce their risk of depression, can be used independently or following the initial intervention noted in this article on "Risk Education" (see Table 3).

Response

DOPPS I and II brought attention to the under-recognition of depression in the people on hemodialysis and the medical team's lack of response to the illness once it is identified. There are many reasons for this occurrence in hemodialysis clinics, one of which is likely to be the assumption that depression is a "normal state of distress" in a person on hemodialysis. The lack of training and continuing education received by

Table 5

A Nephrology Social Work Approach to Preventing Depression

1. Share and dialogue about the findings from Guzman's research with patients. Explain the variables that have been shown to predict depression in dialysis patients. Allow the patient to help assess for these predictors in his/her own personal life situation. Teach basic cognitive-behavioral techniques to offset this risk and encourage patients to self-screen and seek support if these areas lose their balance.
2. Maintain focus on these predictors during your quarterly contacts. Do not assume one discussion about these predictive variables is enough. As patients live through the ups and downs of the illness, they need to be challenged to continue to strengthen their emotional and psychological coping skills in this area.
3. Consider offering annual treatment programs on-site at the dialysis facility. One-evening classes or four-week programs are time-saving and can be very valuable to patients who need additional support and skill-building to guard against depression. They can further prevent depression if they factor in live, small-group support.
4. If risk of depression presents, help patients develop an emotional self-care plan. Helping patients learn to reach back out to others when they isolate, expand into their social roles again, strengthen relationships, reduce relationship conflict, and increase self-esteem can be helpful in reducing the risk of depression.

nephrologists in the medication management of depression is also key. Continuing problems with patient access to outpatient psychiatry, due to insurance and transportation barriers, continue to point to nephrologists as the most likely medical team members to initiate and oversee antidepressant therapy. A final barrier to effective medical treatment of depression is the reality of stigma (Antai-Otong, 2006). Patients and medical team members alike carry the societal value that "toughing" out the emotional ups and downs in life is a sign of strength and worth.

The nephrology social worker has often experienced this stigma firsthand from both the patient and the treatment team when discussing medication or other forms of treatment for hemodialysis patients with depression. The team's sense of "not wanting to approach the patient" or "hoping it will go away" most likely contributes to the persistence of mood disorders in this population. Despite all the reasons for under-attending to treatment, depression is far more than a condition of distress (up to 80% of patients do not measure depressed despite the hardships of life on dialysis). Depression is a medical illness and patients suffer from its symptoms. In that state of suffering, they rely most on their dialysis team for a response to the burden of their discomfort. "Toughing it out" is not likely to produce a remission of symptoms (Soykan et al., 2004). Conversely, it is likely to impede the very survival and quality-of-life outcomes that dialysis teams struggle to achieve (Boulware et al., 2006). To effectively treat depression in people on hemodialysis, the dialysis team must address all of these identified barriers. They must approach patients with comfort and confidence and provide hope that treatment for depression is safe, effective, and medically necessary.

The CNSW OTP "Interventions that Identify and Reduce Depression" (National Kidney Foundation, 1996) provides guidance to nephrology social workers to lead the renal team in this task. This program follows contemporary clinical practice guidelines for depression treatment in medically ill patients by recognizing the value of both antidepressant medication therapy and brief cognitive, behavioral, and interpersonal treatment interventions to reduce depressive symptoms (McCarthur Initiative 2006; National Collaborating Centre for Mental Health, 2004; Spira, 1996; Wexler & Cicchetti, 1992). The depression response protocol found in Table 6 is adapted from the CNSW OTP and can be used to guide nephrology social workers in responding to identified depression. Each step of the protocol will be described in more detail below.

Response: Phase I

In phase one of response, the "acute" phase of treatment, the development of a protocol supported by both the facility nephrologist and the social worker is key. Nephrologists often have preferences regarding treatment of depression in the patients they follow. Some prefer to avoid involvement in this task while others prefer collaborative efforts. Some nephrologists feel more comfortable than others in discussing the benefits of brief psychotherapy or coping skill training. Many are comfortable with the nephrology social worker discussing the benefits of these treatment approaches or the option of combining these with a medication trial, as is often recommended in the literature (American Psychiatric Association, 2000; National Collaborating Centre for Mental Health, 2004). It is essential that these preferences be discussed openly so that social workers and nephrologists can present as an aligned and hopeful team when approaching the patient regarding a

Table 6

Collaborative Nephrology Social Work Roles in Depression Response
Phase 1: “Acute phase” (months 1 to 3):
Discuss positive screening with patient
Explore treatment options, initiate medication trial/ ensure access to care/help patient create plan to ensure adherence
Referral to adjunctive psychosocial skills classes
Phase 2: “Continuation phase” (months 4 to 5):
Speak with patient’s partner to reinforce adherence behavior and monitor for relapse
Rescreen at intervals
Collaborate with physician/pharmacy when necessary to change transplant regimen
Referral to refresher skills classes
Phase 3: “Discontinuation phase” (month 12):
Assessment of need for maintenance therapy
Monitor mood through discontinuation process
Communicate symptoms of relapse. Teach patient/ loved ones to monitor for new episode of depression.

positive depression screen and the need for treatment. Given the sensitivity of the topic for patients, the social worker may prefer to invite the patient to discuss the issue in the privacy of their office or to contact him or her by phone. Nephrologists may also benefit from this private approach as they discuss the initiation of medication treatment for depression. With any approach, the nephrology social worker and nephrologist are likely to present as a team when discussing the issue with a patient identified as depressed.

The facility social worker can offer support in many other ways to a nephrologist faced with the task of depression management. Nephrologists may benefit from the social worker’s efforts to obtain information updates from local pharmacists or pharmaceutical company representatives regarding dosing guidelines for antidepressant medications in people on hemodialysis. The wide range of medications available can be a challenge for nephrologists who may have minimal training in this area and little time to seek out information. The nephrologist may choose an agent that can treat a spectrum of symptoms that accompany depression (e.g., anxiety, irritability, sleep disturbance, apathy, anhedonia, amotivation, and lethargy). If these are unsuccessful, it is possible to then move toward an antidepressant with more specific properties. Studies support the use of selective-serotonin reuptake inhibitors and other agents for the treatment of depression in patients with ESRD as well as patients with comorbid cardiac disease (Cohen et al., 2004; Kimmel et al., 2002; Lesperance et al., 2003).

It is possible for nephrologists to intervene with antidepressant medications to reduce symptoms quickly for people on hemodialysis, but they may lack the time or proximity to carefully monitor a patient’s response to the medication. With studies showing a significant degree of nonadherence to medication prescription in the hemodialysis population, social workers’ support in monitoring the trial and providing educational reinforcement regarding the need for strict adherence to the medication can be essential to good outcomes (Curtin et al., 1999). Social workers’ brief contact with patients is perhaps most critical during the first few weeks of therapy when side effects are most pronounced and when patients are the most likely to withdraw from therapy. Social workers can also solicit telephone support for patients from pharmacists during this period. Pharmacists may, in turn, contact nephrologists regarding possible changes in medications or dosing to offset early side effects. These efforts can improve early adherence and prevent patient withdrawal from medication therapy. When adherence behavior appears poor, social workers can notify physicians of the risk so that the use of medication therapy can be re-evaluated or discontinued. In cases in which several agents do not provide a remission from symptoms, psychiatric consultation can be encouraged to reduce nephrologists’ burden. Social workers can help nephrologists coordinate referral and access to psychiatric consultation. Nephrology social work support of nephrologists may also be valuable in insurance coordination for antidepressant medications, should special authorization be needed after unsuccessful formulary medication trials.

Should an individual on dialysis not be a candidate for antidepressant medication therapy, or desire more than medication treatment for depression, brief psychotherapy interventions are available in the NKF-CNSW depression management programs (Cabness et al., 2006, National Kidney Foundation/Council of Nephrology Social Workers, 2006). Based on Guzman’s research that isolated the predictors of depression in people on hemodialysis, these interventions can be led by nephrology social workers in the dialysis clinic classroom or chairside with patients as they undergo dialysis treatment. Using cognitive, behavioral, and interpersonal interventions, these brief, weekly (for a period of 3 to 6 weeks) social work interventions build psychological tools and coping skills that can help people on hemodialysis gain control of their moods (Johnstone, 2005). In some clinics, these programs are being offered on an annual or biannual basis to provide depression prevention, and depression management services. Physician referral to these on-site programs can improve motivation to attend. Contemporary treatment guidelines support combining this type of treatment with medication to enhance depression treatment outcomes, especially for patients with problems of social adjustment and interpersonal relationship during phase II of treatment following the remission of depressive symptoms (American Psychiatric Association, 2000; Beck, 2005; Fava et al., 2004; Petersen, 2006; National Collaborating Centre for Mental Health, 2004). This team approach between social workers and nephrologists in phase I can help patients to accept and move through the acute phase of treatment for depression. It can also ensure that they are well on their way toward remission. The stabilization period typically lasts 12 weeks for medication therapy. With regard to psychotherapy, although many models of cognitive-behavioral therapy suggest a 10- to 12-week treatment course, people on hemodialysis have demonstrated improvement in mood after 3 to 6 sessions of coping skills training classes (using a cognitive-behavioral approach) when measured by the Cognitive Depression Inventory, the Beck Medical Fast Track, and patient self-report (Blount 1998; Cabness et al., 2006; Johnstone, 2005).

Response: Phase II

In phase two of the depression response process, known as the “continuation phase,” the social worker can help monitor the patient’s response to treatment. This phase typically lasts 4 to 5 months following full remission of symptoms. In this phase, social work inquiry or screening can monitor for the risk of relapse. Relapse during this phase can occur due to a change in response to the medication itself, a reaction to any new medications prescribed during the course of treatment, or use of illicit substances that interfere with medication actions. Improper patient dosing of the medications (nonadherence) can also stimulate a relapse of symptoms. In addition, improper medication use can worsen mood, as neurotransmission is chaotically altered.

Following treatment with psychotherapy, a relapse can also be triggered by a worsening of a patient’s life situation such as a change in medical status, interpersonal relationship stress, or a reactivation of depressive thinking styles (Kimmel & Patel, 2003; Segal et al., 2006). Nephrology social workers can be invaluable to patients and physicians by ensuring that any changes in patients’ moods or functioning are communicated during the continuation treatment phase. If subsequent changes are made in the treatment regimen, social workers can ensure that patients understand those changes and have access to new therapies prescribed. Monthly contacts or phone calls to patients to track mood and identified symptoms can promote adherence and offset relapse risks to maximize treatment outcomes during this phase. These phone calls can reinforce the importance of medication compliance. If patients have undergone adjunctive psychosocial/coping skills training with nephrology social workers, a monthly follow-up call can reinforce some of the cognitive/behavioral concepts that help manage mood. It can also screen for any barriers to using the tools that were prescribed in their training.

During the continuation treatment phase, nephrology social workers can also effectively serve as “life coaches” to encourage patient re-entry into previous, pleasurable activities. Using materials from the NKF/CNSW OTPs, social workers can guide patients to push back out into the world again, reduce isolation, and regain emotional confidence. These social work interventions can provide the impetus for rehabilitation, which is often needed following the impact of depression on patients and their larger worlds.

Simple tracking tools can be used to assist facility social workers with the clinical case management tasks of the continuation treatment phase. Table 7 displays a tracking tool that was adapted from Sarfaty and the FMCNA Western Massachusetts Social Workers. In addition to tracking activities during this treatment phase, providing helpful assignments to patients and their significant others during this period can also be a helpful social work role. Loved ones often want to participate in patient rehabilitation efforts during this treatment phase but lack guidance in how to be helpful. With the patient’s consent, guiding loved ones to help track mood and participate with the patient in pleasurable activity can give them a sense of being a “partner” in the patient’s recovery from depression.

Table 7

Social Worker Depression Screening, Education and Treatment Activity Tracker

Patient: ______________________ **Age** ______ **1st Tx ever**_____ **1st Tx this unit**_______ **Social Worker:**__________________

MEDICATION HISTORY and UPDATE: AntiDepressant/AntiAnxiety/Other Psychotropic Med? Y/N Comment:___________________

____

____

____

Date of Depression Screening	Screening Score	SW Interpretation/Comments

Date of SW Contact	Time Units (15 min units)	Nature of SW Contact/Intervention:*(CBT/IPT/Fam. educ, couns/Meds review, other)*	Additional Comments

Hospitalization (dates)	Missed Treatments (dates)

Adapted from C.Sarfaty, MSW, FMCNA, Southern New England

DEPRESSION RISK FACTORS: (Check all)

____**Diabetes**
____**Cardiac Disease/CHF/CAD**
____**Stroke**
____**Vascular Disease (PVD)**
____**Amputation**
____**Pt Reported Hx of Depression**
____**Other:**____________________________________
____**GI Bleeding**
____**Cancer**
____**Lung Disease**
____**Social Isolation**
____**Anxiety**

Response: Phase III

Phase III of the depression treatment process, known as the "maintenance or discontinuation phase," arrives approximately 1 year after the ongoing remission of symptoms. At that time, nephrology social workers can assist physicians in re-assessing patients' treatment responses and their recovered level of bio-psycho-social functioning. In patients who have chronic life stressors (including medical illness), previous episodes of depression, or if they have a relapse following discontinuation of medication therapy, maintenance therapy is often medically advisable (American Psychiatric Association, 2000; National Collaborating Centre for Mental Health, 2004; Viguera et al., 1998). Nephrology social workers, who have closely witnessed the patient's response to treatment over the course of a year, can join the discussion regarding the need to continue medication therapy. This unique relationship between patients and social workers in the dialysis clinic offers a valuable angle of observation, which is perhaps why nephrology social workers are so perfectly posed to help lead the response to depression in the people on hemodialysis.

Should the patient be interested in discontinuing medication following a course of treatment, nephrology social workers can partner with nephrologists to help supervise the discontinuation process. Because symptoms of discontinuation often mimic symptoms of relapse, regular contact with the patient and communication with nephrologists during rounds can help monitor the patient's discontinuation response. Discontinuation symptoms that do not remit when weaning the dose slowly signal the possibility of relapse and the need to re-establish dosage for continued treatment. This process is one that could take time and benefit from the encouragement and objectivity of social workers, who can assist patients in contacting nephrologists for guidance. If patients feel strongly about discontinuation of treatment, this is another point in time in which social workers can help patients access outside psychiatric consultation at the nephrologists' request.

If therapy discontinuation is successful, nephrology social workers can help people on hemodialysis understand the risk of a future episode of depression. Patients and their loved ones can be taught how to monitor for signs and symptoms of a recurrence. Regular screening can be combined with patient self-monitoring to detect the need for re-initiation of treatment (with medication or psychosocial intervention classes) before a new episode of depression worsens.

The three-phase model discussed in the previous paragraphs allows nephrology social workers in dialysis facilities to collaborate with physicians in responding to and ensuring effective depression treatment in people on hemodialysis. This model, which monitors patient response closely from the initiation of treatment until the maintenance or discontinuation phase, is likely to improve nephrologists' sense of safety with, and encourage utilization of, available medications for people on hemodialysis who have depression. It is also likely to ensure the delivery of adjunctive psychosocial interventions that can improve depression treatment outcomes and guard against relapse.

SUMMARY

DOPPS provided evidence to support the practice of early screening for and treatment of depression to improve the quality of life and survival of people on hemodialysis worldwide. Studies following DOPPS continue to point out the benefits of identifying and treating depression in this population (Boulware et al., 2006; Hedayati et al., 2004). As a modifiable variable in several quality outcomes, it is clearly a target for effective renal disease management. There are methods now available that can effectively screen for and manage depression in people on hemodialysis. There are established relationships in place between patients and mental health providers (nephrology social workers) on the dialysis treatment team. That team member is ready and seated at the CQI table. The trend in health care is to provide these depression management services at sites where patients are more willing to accept them because of the familiarity and trust they have established with their medical providers. This on-site programming is cost-effective (Simon et al., 2001). Finally, as illustrated in this article, there are models and processes available to guide nephrology social workers to help lead depression management programming at the dialysis clinic site and in collaboration with the renal team. The time is now to move forward in implementation of these approaches. According to DOPPS, the costs of *not* doing so, for patients, dialysis providers, Medicare, and the industry, are likely to be significant.

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DOPPS: Making the Case for Using Functioning and Well-Being Surveys to Assess Risk and Improve Outcomes

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The prevention of frailty and dependence optimizes dialysis patients' quality of life and has the potential to reduce the overall costs associated with their care.

—Christopher Blagg, MD, Nephrologist

(Life Options Rehabilitation Advisory Council, 1994)

Multiple studies of people with chronic kidney disease and kidney failure included measurement of functioning and well-being using the SF-36 or the Kidney Disease Quality of Life™ survey. Those on dialysis have scored consistently lower than norms. The Dialysis Outcomes and Practice Patterns Study found that in patients on hemodialysis low physical component summary and mental component summary scores were significantly associated with higher risks of hospitalization, death, and dialysis withdrawal. Higher scores on the "down in the dumps" and "downhearted and blue" questions were significantly associated with higher risk of hospitalization, death, and dialysis withdrawal. Preliminary research has found that rehabilitation interventions can improve functioning and well-being and that scores can help direct team care planning. More research is needed to determine which clinical social work interventions are associated with improved scores and outcomes. Answering this question could greatly improve the lives of those with kidney disease, save taxpayers' money, and help dialysis centers stay financially viable.

INTRODUCTION

Research has shown that even if new patients on dialysis never ask these questions out loud, most want to know "How long will I live?" and "How well will I live?" (Juhnke & Curtin, 2000). The question "How well will I live?" reflects the patient's deeply personal concern about quality of life with chronic kidney disease (CKD) and its treatment.

One of the eight "articles of faith" of good medical care states "Good medical care treats the person as a whole" (Lee & Jones, 1933). In 1948, the World Health Organization (WHO) defined health as a "state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). Functioning is so important that the WHO added a classification scheme for functioning and health called the International Classification of Functioning, Disability and Health (ICF). However, it took Congress nearly 40 years to reiterate the importance of improving end-stage renal disease (ESRD) quality of care by improving clinical outcomes and patient functioning and satisfaction.

Since 1976, the Conditions for Coverage for Suppliers of ESRD Services have mandated that "the patient care plan is personalized for the individual, reflects the psychological, social, and functional needs of the patient, and indicates the ESRD and other care required as well as the individualized modifications in approach necessary to achieve the long-term and short-term goals." To accomplish this, the regulations also require that all dialysis clinics have a qualified social worker who has a master of social work degree with clinical specialization from a graduate school accredited by the Council on Social Work Education and a license (if required by the state). These regulations mandate that:

> [S]ocial services are provided to patients and their families and are directed at supporting and maximizing the social functioning and adjustment of the patient. Social services are furnished by a qualified social worker (§ 405.2102) who has an employment or contractual relationship with the facility. The qualified social worker is responsible for 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 groupwork 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 and families to utilize them (42 CFR 405 Subpart U).

Since the late 1980s, the federal government and renal community have invested much in an attempt to address quality of care. The Omnibus Budget Reconciliation Act of 1987 mandated that the Institute of Medicine (IOM) examine patient quality of care measured by three variables: clinical indicators, functional status, and satisfaction (Rettig & Levinsky, 1991). Key initiatives included:

- A series of IOM conferences and reports on health status outcomes and quality of care for patients with kidney failure (Lohr, 1989, 1992; IOM, 1990; Rettig & Levinsky, 1991; Rettig & Lohr, 1994; Schrier et al., 1994).
- Collaboration between the Health Care Financing Administration (now Centers for Medicare and Medicaid Services [CMS]) and the ESRD Networks to develop the Core Indicators Project (McClellan et al., 1999).
- Development of guidelines by panels of experts to identify, classify, stratify, and treat patients with kidney failure at all stages of kidney disease through the National Kidney Foundation (NKF) Dialysis Outcomes Quality Initiative (DOQI; Eknoyan et al., 2000) and Kidney Disease Outcomes Quality Initiative (K/DOQI; National Kidney Foundation, 2002).
- Congress even mandated that CMS "implement...a method to measure and report quality of renal dialysis services under the Medicare program" leading CMS to choose 16 clinical performance measures to track based on the DOQI guidelines (Public Law 105-33, 1997).

The CMS, ESRD Networks, and NKF guideline initiatives have focused entirely on improving clinical indicators—treatment of anemia, dialysis adequacy and vascular access, nutrition, and the medical conditions that contribute to or result from kidney damage. As Figure 1 shows, over the 10-year period from 1994 to 2004, while the Core Indicators Project, DOQI, Clinical Performance Measures and K/DOQI initiatives were progressing, the U.S. annual adjusted mortality rate declined by a mere 1.1% (U.S. Renal Data System, 2006). One has to wonder: What are we missing? One explanation that should be considered is that the renal community's focus on "clinical indicators" has largely ignored the importance of functioning and well-being (FWB) and facilities' assignments of non-clinical tasks to social workers has denied patients access to social workers' clinical interventions.

Focusing on disease of the kidney or other organs and tissues of the body ignores the person who is *experiencing* the disease and its limitations. By ignoring the patient's physical and mental functioning, the renal community has failed to adequately answer the question that patients want to know: "How well will I live?" This article focuses on the research basis for why it is important for social workers to assess and treat deficits in FWB in a person with kidney disease. By providing clinical interventions to address these deficits, social workers can help the renal community improve how long and how well patients live.

Figure 1

U.S. Dialysis Mortality Rate and Clinical Interventions 1994–2004

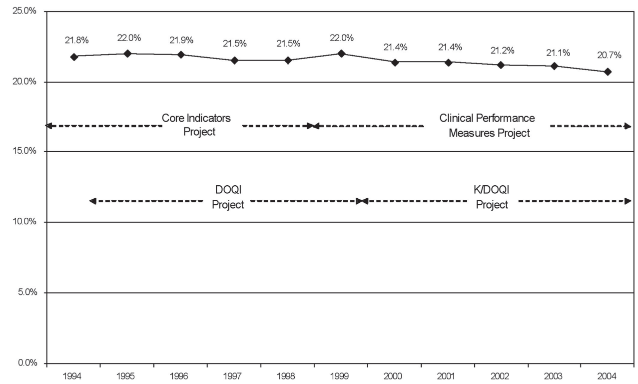

Figure 1. Annual adjusted mortality rate: all dialysis patients. From day one to 1 year + 90 days, by age, gender, race, ethnicity, primary diagnosis, and vintage.

BACKGROUND

In 1993, the IOM sponsored a conference entitled Measuring, Managing, and Improving Quality in the End-Stage Renal Disease Treatment Setting (Schrier et al., 1994). In addition to many presentations on clinical outcomes, two addressed FWB. One reported a study of 112 patients who completed the Medical Outcomes Study SF-36 quarterly for an average of 14 months. The SF-36 measures domains including physical functioning, pain, energy/fatigue, role limitations caused by physical health, role limitations caused by emotional health problems, social functioning, emotional well-being, and general health perceptions. Scoring of the various measures yields two summary scores: the physical component summary score (PCS) and the mental component summary score (MCS). The study revealed that staff's assessments of patient functioning were quite different from patients' self-reports and were "very naive," and "neither systematic nor consistent." However, patients told interviewers the survey helped them describe their health more fully than they routinely did with staff. Dialysis patients had lower FWB scores than the general U.S. population on all scales except social functioning. Dialysis staff used survey scores to determine who needed referral to physical therapy and treatment for depression. The author concluded that completing the surveys empowered patients to participate more in their own care (Meyer et al, 1994).

The second report discussed a number of surveys available and described the benefits of generic instruments (e.g., the SF-36) that allow comparisons to the general population, and the benefits of disease- or treatment-specific surveys like the Kidney Disease Quality of Life™ (KDQOL), that allow assessment of the effects of a disease or treatment on scores. The author encouraged staff to use these surveys in clinical practice to identify necessary care and treatment and to track changes in functioning based on that treatment (Kutner, 1994).

In 1994, the IOM convened another workshop to evaluate and recommend multiple FWB survey instruments. Members of the Health Status Outcomes Group reviewed survey instruments for reliability, validity, ease of use, patient friendliness, and cost, and recommended four: the Dartmouth COOP Charts, the DUKE Health Profiles, the KDQOL, and the SF-36. It was also recommended that FWB be one-third of patient assessment along with physical findings and lab tests. The rationale given was that the inclusion of FWB assessment costs little and is appreciated by patients who receive feedback and interpretation of results (Rettig et al., 1997).

Early studies questioned whether a link would be established between FWB and clinical data and between care processes and outcomes. A historical prospective study of 1,000 patients on hemodialysis at three facilities established the link between FWB scores and outcomes, such as hospitalizations, death, missed treatments, and depression (DeOreo, 1997). In the study, patients who scored below the facility's median on the SF-36 were found to be twice as likely to die and one and a half times as likely to be hospitalized compared with those who scored above the median. The probability of survival increased 10% with each 5-point increase in the PCS score on the SF-36 and a 5-point increase in the PCS reduced hospitalization days nearly 6%. Those who missed two treatments at least twice a month ("skippers") were more likely to have higher PCS scores and lower MCS scores. The MCS and/or mental health score identified that 25% of patients at these facilities were depressed.

Development of the KDQOL-SFTM (short form) instrument and correlations of scores with patient outcome measures was discussed in a 1994 paper. The KDQOL-SF includes the SF-36 and kidney disease-specific questions measuring domains including symptoms/problems, effects of kidney disease, burden of kidney disease, work status, cognitive function, quality of social interaction, sexual function, sleep, social support, dialysis staff encouragement, and patient satisfaction. The 80-question instrument takes about 16 minutes to complete and has been translated into multiple languages. It was administered to 165 patients at 9 dialysis clinics. Findings included hospital days in the prior 6 months were significantly correlated with 14 of the 19 kidney scales, and the emotional well-being scale correlated the most with hospital days. Number of medications the patient took correlated with 9 of the 14 kidney scales and physical functioning correlated most with number of medications. The authors recommended the KDQOL-SFTM as a valid and reliable measure of treatment effectiveness (Hays et al., 1994).

The NKF-K/DOQI work groups reviewed FWB research in the development of CKD guidelines. As a result, the guidelines recommend that clinicians (usually social workers) assess functional status early and regularly, especially as health setbacks or changes in therapy occur, and research studies be conducted to determine what clinical and rehabilitation interventions improve patients' functioning and reduce hospitalizations and death (NKF, 2002).

In 1996, a study of nearly 14,000 Fresenius Medicare Care patients examined clinical parameters, patient characteristics, hospitalizations, and deaths. The SF-36 was administered by social workers and completed by 13,952 patients. In this study, PCS scores below 43 and MCS scores below 51 were associated with higher risk of death. With each 1-point increase in PCS, the relative risk of death or hospitalization dropped by 2%. Each additional point in the MCS reduced the relative risk of death by 2% and hospitalization by 1%. The authors concluded that PCS and MCS measure something unique not accounted for by lab values or case mix. They encouraged the use of FWB surveys to prevent further decline in functioning by targeting interventions designed to address functional deficits (Lowrie et al., 2003). Today, many social workers regularly assess patients using FWB surveys; their scores help to direct social work clinical practice.

THE DIALYSIS OUTCOMES AND PRACTICE PATTERNS STUDY

The Dialysis Outcomes and Practice Patterns Study (DOPPS) is an observational prospective study in nationally representative hemodialysis facilities. It began in 1996 and continues into the present. Phase I included 17,236 hemodialysis patients (full health-related quality of life data available on 10,030) in

148 nationally representative facilities in the United States, 101 facilities in five European countries (France, Germany, Italy, Spain, and the United Kingdom), and 65 facilities in Japan (Mapes et al., 2004). DOPPS II expanded to include 9,382 patients from Australia, Belgium, Canada, Italy, Japan, New Zealand, Spain, Sweden, the United Kingdom, and the United States (Lopes et al., 2004). The study examines relationships between patient sociodemographic and comorbidity variables and dialysis facility practice patterns with four primary outcomes—mortality, hospitalization, vascular access, and quality of life. In addition to comprehensive data collected on patient demographics, lab values, comorbidities, and treatment, more than 10,000 patients completed the KDQOL survey in participating facilities. Along with PCS and MCS scores from the SF-36, a kidney disease component summary (KDCS) score from disease-specific questions was obtained. Researchers wanted to learn whether PCS, MCS, and KDCS scores were associated with mortality and hospitalization rates. Because the survey includes two specific questions on depression, researchers were also interested in investigating the prevalence of patient depression and possible associations with the same study outcomes.

Low FWB Scores and Risks of Hospitalizations and Death in DOPPS Overall

DOPPS researchers found that low PCS, MCS, and KDCS scores across all countries were predictive of an increased risk of death and hospitalization, independent of demographic factors and comorbidities. As PCS, MCS, and KDCS scores decreased, statistically significant risks of death and hospitalization increased (see Figures 2 and 3; Mapes et al., 2003).

Figure 2

Adjusted Relative Risk of Death for Quintiles of Albumin and HRQOL Components

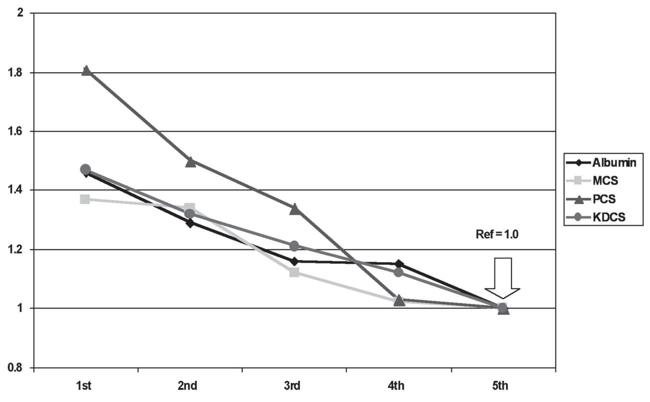

Figure 2. Adjusted relative risk of death for quintiles of albumin and Health Related Quality of Life (HRQOL) components.

Figure 3

Adjusted Relative Risk of Hospitalization for Quintiles of Albumin and HRQOL Components

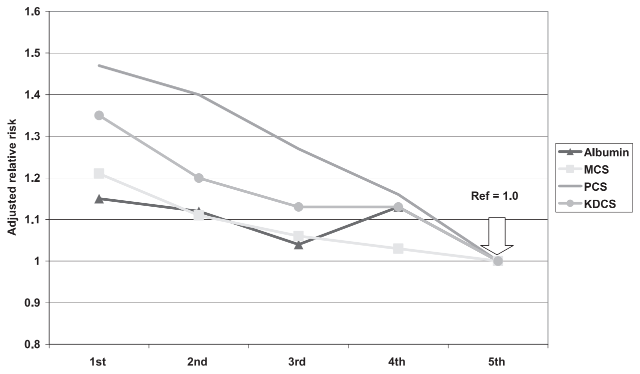

Figure 3. Adjusted relative risk of hospitalization for quintiles of albumin and HRQOL components.

In Figures 2 and 3, the relative risks for death and hospitalization were statistically significant at $P < 0.001$, except for hospitalization and albumin, which were significant at $P < 0.05$ (Mapes et al., 2003).

Patients who scored 10 points less on PCS had a 25% higher death risk and a 15% higher risk of first hospitalization. Those scoring 10 points lower on the MCS had a 13% higher death risk and a 6% higher risk of first hospitalization. Those with 10-point lower KDCS scores had an 11% higher death risk and a 7% higher risk of first hospitalization. Although MCS and KDCS were not as strongly associated with risk of hospitalization and death as PCS, they were still statistically significant. Patients with PCS scores in the lowest quintile had a 56% higher risk of hospitalization and a 93% higher risk of death compared with those in the highest quintile.

Albumin has long been considered the strongest independent predictor of poor outcomes in patients on dialysis. This study found that low PCS, MCS, and KDCS scores were at least as powerful in independently predicting hospitalization and death as albumin death risk (Mapes et al., 2003). The logical conclusion is that it is just as important to collect and respond to patient self-report FWB scores as it is to collect and respond to laboratory data.

DOPPS researchers also examined differences among patients in the United States, Europe, and Japan. Patients in the United States had the most comorbidities and patients in Japan had the least. People on dialysis in all countries scored lower on the SF-36 questions in the KDQOL than the general population within each country. U.S. patients scored lower on PCS and higher on MCS than patients in Europe or Japan. Japanese patients scored higher on PCS and reported a greater burden of kidney disease than patients in the United States or Europe. Rates of employment were lower (16.8%) and disability rates were higher (36.0%) in the United States compared with Europe (26.8% and 20.0%, respectively) and Japan (53.3% and 4.0%). The authors recommended further research to find ways to improve physical functioning and reduce the burden of illness (Fukuhara et al., 2003).

Another question of interest in DOPPS was whether ethnicity was associated with FWB scores and hospitalization or death. Results indicated African American patients had higher PCS, MCS, and KDCS scores than white patients. Asian and Hispanic patients had higher PCS scores but did not score higher on MCS or KDCS compared with white patients. Compared with white patients, Native American patients scored lower on MCS and mental health. African American, Asian, and Hispanic patients all scored lower on patient satisfaction, but only in African American patients was this score significantly associated with increased death risk (Lopes et al., 2003). The authors suggested additional studies to further understand possible ethnic influences in FWB scores and to determine what interventions in low-scoring patients reduce hospital and death risks (Lopes et al., 2003).

Depression and Risk of Hospitalization and Death

There is substantial evidence that depression is a central component of health-related quality of life and is too often undiagnosed and untreated in people with kidney failure. Research has shown an association between depression and poor outcomes, including missed treatments, hospitalization, death, and suicide (DeOreo, 1997; Kimmel et al., 2000). The DOPPS researchers investigated the association between physician-diagnosed depression in the medical record and/or patient self-reported depression on the KDQOL and hospitalizations, death, and withdrawal (Lopes et al, 2003). The analyses included differences in outcomes if a patient record showed antidepressants had been prescribed. In U.S. and European patients on hemodialysis, depression was independently associated with mortality and hospitalization, even when adjusted for comorbidities, years on dialysis, sociodemographic variables, and country. In fact, DOPPS data showed that 19% of U.S. patients were diagnosed as depressed by physicians compared with 16.2% of European patients. Those who were older, not white, and employed were less likely to be diagnosed as depressed by a physician. Because so many patients are not diagnosed as depressed, these patients may be depressed but do not express depression in the way doctors expect.

In the United States, 36.6% of physician-diagnosed patients were prescribed antidepressants, compared with 12.1% of those in Europe. Excluding patients prescribed antidepressants and adjusting for sociodemographic factors, comorbidities, years on dialysis, and country, patients diagnosed as depressed by a physician were 25% more likely to die, 11% more likely to be hospitalized, and were more likely to withdraw from dialysis. Those diagnosed with depression by physicians were more likely to die from cardiac disease, infections, and vascular causes.

Researchers classified patients as depressed by self-report if they responded to either of two SF-36 questions—“Have you felt so down in the dumps that nothing could cheer you up?” and “Have you felt downhearted and blue?”—with a 4 (a good bit of the time), 5 (most of the time), or 6 (all of the time). Self-reports of depression were higher among U.S. patients. Those who self-reported depression on the “down in the dumps” question were more likely to be younger, high school graduates, unemployed, have diabetes, lung disease, or gastrointestinal bleeding. Patients who self-reported depression on “so down in the dumps,” “downhearted and blue,” or both had a statistically significant higher risk of dying, being hospitalized or withdrawing from treatment compared with those who did not self-report depression. In those who were not physician-diagnosed, the “so down in the dumps” question was more strongly associated with mortality risk than the “downhearted and blue” question. A patient who self-reported depression on either or both of the two questions was more likely to be hospitalized. Interestingly, whether a patient was prescribed antidepressant medications did not significantly alter the risks of death or hospitalization. It is unknown whether adding counseling would have altered these risks. The authors recommended asking the “so down in the dumps” question to identify and target at-risk patients and implement medical and psychosocial interventions designed to reduce risks of hospitalization and death (Lopes et al., 2002). Social workers could easily add these two questions to their initial psychosocial assessment to perform an initial screening for depression.

In the second phase of the DOPPS, researchers administered the Center for Epidemiologic Studies Depression (CES-D) screening index to people on hemodialysis

(Lopes et al., 2004). Scores of 10 or higher on the 10-question CES-D short form indicate likely depression. Only 13.9% of patients had been diagnosed with depression by their physician, whereas the CES-D identified 43% of patients as depressed. Patients were more likely to be diagnosed as depressed by their physician and to have been identified by the CES-D as depressed if they were female, unemployed, had a low serum albumin level, and debilitating comorbidities.

DOPPS also examined the relationship between clinical outcomes, those identified as depressed on the CES-D, and those diagnosed by physicians as depressed. Researchers found that those scoring at or higher than 10 on the CES-D were more likely to die, be hospitalized, or withdraw from treatment. Patients who were physician-diagnosed as depressed were more likely to die or withdraw from dialysis, but were not more likely to be hospitalized.

Of patients who were diagnosed as depressed by their physician, only 38.9% of U.S. patients were prescribed antidepressants. Whether or not a patient with self-reported depression had been prescribed antidepressant medications was not significantly associated with mortality.

The DOPPS researchers found agreement between the SF-36 “downhearted and blue” question and scores of 10 or higher on the CES-D. They were unable to test the “so down in the dumps” question because it was not in the second phase of the DOPPS, but they believed it would have as strong an agreement with the CES-D as with the “downhearted and blue” question. The 10-question CES-D and the two SF-36 questions were all predictive of hospitalization and death. Depression is too often undiagnosed and untreated. Therefore, the authors suggested that clinicians screen patients to identify and treat those at risk to reduce hospitalizations and death (Lopes et al., 2004).

THE LINK BETWEEN INTERVENTIONS, FWB SCORES, AND OUTCOMES

Some believe that research has not yet established what interventions will improve FWB scores and outcomes in dialysis patients. Although more work needs to be done to assess interventions, we know that some interventions have improved these scores and/or outcomes.

Research has shown that patients who are not physically active will become more debilitated over time—what Dr. Patricia Painter has called the “cycle of deconditioning” (Painter, 1994). A 2-month home exercise intervention followed by a 2-month, in-center intervention improved PCS scores. In fact, in patients with PCS scores less than 34, exercise improved these scores by an average of 7 points (Painter et al., 2000). Because the intervention was brief, it was impossible to determine the intervention’s effect on mortality. However, if one accepts multiple studies that document a significant association between low PCS scores and morbidity and mortality, one can see that improving PCS scores through exercise could reduce hospitalization and death rates.

The Medical Education Institute, Inc. conducted a study in the ESRD Network of Texas for the Life Options Rehabilitation Program. A total of 169 Fresenius dialysis clinics reported clinical, demographic, and facility characteristics; mean PCS and MCS scores for facilities; and used the Life Options Unit Self-Assessment Tool (USAT) to report rehabilitation activities. USAT rehabilitation activities are separated into five categories: encouragement, education, exercise, employment, and evaluation. The mean USAT score for participating Texas facilities was 36.67 out of a possible 100 points. The lowest mean score was for exercise with a mean score of 3.71 out of 20. The only significant association with facility-level MCS scores was a higher facility USAT score, indicating that the clinic offered more rehabilitation activities.

Fresenius social workers studied in-center hemodialysis patients to determine if rehabilitation goal setting could be enhanced by following a four-step process using the SF-36 and interdisciplinary team planning. Five clinics served as a control group, receiving usual care. In five other demographically comparable clinics, surveys were administered and interventions undertaken. The social worker explained and administered the SF-36, reviewed the results with patients, and asked patients to identify functioning or well-being goals to work on over the next four months. The social worker explained the SF-36 and shared patients’ results and goals with the interdisciplinary team. All team members were asked to help design interventions—social, vocational, emotional, physical, and functional—to help the patients achieve their rehabilitation goals. After four months, the SF-36 was administered again and patients were asked “How close are you to the goal we set four months ago?” The two role disability scales—role physical and role emotional—improved significantly. Patients had set goals such as feeling stronger, being able to make their own beds, doing household chores, gardening and fishing again, feeling less lonely and anxious, taking care of grandchildren again, and being less dependent on family. Forty-two percent of patients met their goals, 46% made progress, and only 12% reported no progress toward goals (Callahan et al., 1999).

IMPLICATIONS FOR CLINIC SOCIAL WORK PRACTICE

As can be seen from these studies, FWB surveys help identify people on hemodialysis who are at risk of hospitalization, death, and withdrawal. Two simple questions from the SF-36 identify depressed patients; depression is associated with increased risk of hospitalization and death. Social workers may want to add the “so down in the dumps” and/or “downhearted and blue” questions to their routine assessments to screen for depression without having to administer a longer depression survey. Once social workers identify patients who are at risk because of depression or low PCS or MCS scores, it would be important to alert the team that the patient is unstable and needs monthly team care planning and to report the scores to the patient to seek verification and feedback. If the patient attends the team care planning meeting, the social worker can review the scores with the team and encourage the patient to relate the factors that may have contributed to his or her low scores. Sharing this information in this way would allow the patient and the team to partner together to design clinical and psychosocial intervention plans and timelines with the goal of improving FWB scores and ultimately reducing the patient’s risk of hospitalization and death.

Social workers who understand the research basis for FWB measurement may want to share these connections with renal staff, administrators, and the dialysis corporation leadership.

1. Patients on dialysis have multiple comorbidities, become more debilitated over time, and more than 21% die each year, despite clinical guidelines, monitoring laboratory and other clinical measures, and clinical interventions designed to improve clinical outcomes.
2. DOPPS and other studies have shown that low PCS, MCS, and KDCS scores are significantly associated with key outcomes, including hospitalizations, deaths, and missed treatments.
3. Social workers regularly interview patients to identify their individual psychosocial needs, maximize their FWB, and participate in care planning. A social worker can complete an FWB survey during a routine patient contact and collect data about how the patient experiences kidney disease and dialysis.
4. Social workers can easily learn how to administer, score, interpret, and report to patients the results of surveys. Free online tools are available for this purpose for the KDQOL at **www.gim.med.ucla.edu/kdqol/**.
5. Social workers may believe that patients will resist completing FWB surveys. However, social workers have reported that patients do not oppose completing these surveys when they know the purpose, receive feedback and offer input regarding their scores, and are allowed to partner with the team to achieve their goals.
6. When the team understands the surveys, knows the patients’ goals, and designs interventions to encourage patients to meet their goals, scores can improve and most patients will make progress or reach their goals. As a result, the team can gain better understanding of their patients’ attitudes and feelings.
7. Reducing the number of missed treatments and hospitalizations and increasing patient survival assures maximum utilization of dialysis equipment, keeps patients in clinics instead of in the hospital, and improves clinic revenues. Providing social workers time and administrative support to survey and treat at-risk patients could increase clinic profitability.

CONCLUSION: A CALL TO ACTION

DOPPS data demonstrates that measuring FWB is key to identifying patients at risk for poor outcomes. FWB surveys supplement information professionals can glean from clinical data and patient interviews. Without data from such surveys, staff frequently misjudge patients’ quality of life and may make care planning decisions based on their misjudgments.

Social workers need to have the time and administrative support to learn how to administer, score, and interpret FWB surveys. These surveys are an important component to a social worker’s clinical resources. Using survey results to direct practice may improve how long and how well patients live and could dispel misperceptions of social workers. One such misperception is revealed in the following comment to the proposed Conditions for Coverage, in which CMS is asked to protect patients by deleting the requirement that social workers provide counseling:

> We believe the proposed requirement to provide counseling services and long-term behavioral and adaptive therapy is fraught with potential patient danger and is not reflective of the realities of the functional role of the social worker in dialysis facilities....and the expansion of their activities into this role provides a potential minefield of potential unwanted clinical results...Social

> workers spend a great percent of their time providing for the ‘social’ requirements of patients. This can be focused on food, clothing, shelter, transportation, and financial resources (including Medicare and insurance coverage). These are major factors contributing to the well-being of patients (McAllister et al., 2005).

Helping patients meet the day-to-day financial burdens of kidney disease is one aspect of a nephrology social worker’s role. However, there are many other roles that social workers can and should fulfill. These include:

- assessing patients’ current status, needs, strengths, and resources
- educating patients and their loved ones about managing kidney disease and feeling more hopeful about the future
- promoting improvement in physical functioning
- advocating for services patients need within the clinic and in the community
- helping patients keep their jobs or find new ones, go to school, and participate in as many age-appropriate activities as possible

A social worker who fulfills these roles will help patients live longer and better, assume more control over their health and their lives, and achieve maximum rehabilitation, while also improving the clinic’s payer mix. Instead of waiting for someone to give patients fish that will feed them for a day, social workers can and do help patients learn to fish so they can feed themselves and their families for a lifetime.

FWB surveys are essential in assessing patients and giving them a chance to tell the renal team what help they need. A mortality rate of nearly 21% is too high when validated surveys are available and the federal regulation requires clinically trained social workers to provide psychosocial services in every dialysis clinic. Using FWB surveys to identify at-risk patients and developing individualized interdisciplinary care plans that include clinical and psychosocial interventions designed to meet patients’ needs and goals may reduce morbidity, mortality, and the burden of kidney disease on the patient, payers, and society. To continue to ignore patients’ FWB and not use social workers’ clinical training and skills shortchanges patients, the social work profession, the renal community, and society.

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Diabetes: The Dialysis Outcomes Practice Patterns Study Results and Innovative Patient Care Programs

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Diabetes is now the leading cause of chronic kidney disease (CKD) in the United States and is also growing in numbers worldwide. The cost of caring for people with diabetes and CKD is escalating and is especially highest from the month prior to starting dialysis to 6 months after beginning dialysis. According to the Dialysis Outcomes Practice Patterns Study (DOPPS), a person with kidney failure who also has diabetes is at higher risk for hospitalization, mortality, retinopathy, blindness and lower limb amputation. The dialysis health care team is challenged to develop new methods of caring for people with diabetes and CKD. Innovative programs reviewed in this article show improved clinical outcomes and an increase in patients' ability to self-manage their disease.

Diabetes is the leading cause of chronic kidney disease (CKD) in the United States. Approximately 45% of kidney failure patients have diabetes, which is a startling increase from 18% in 1980 (U.S. Renal Data System, 2005). The number of people with diabetes living in the United States is also rising. About 20 million people in the United States have diabetes, and more than 150,000 people have kidney failure as a result of diabetes. In 2003, care for people with kidney failure cost the United States more than $27 billion (U.S. Renal Data System, 2005). In 2002, $132 billion was spent on the care of diabetes in the United States (Centers for Disease Control and Prevention, 2005). The cost of someone with diabetes headed toward kidney failure shows a marked increase in the month prior to starting dialysis and in the first 6 months of dialysis treatment (Joyce et al., 2004). Experts in diabetes at the Mt. Sinai School of Medicine estimate that there are 150 million people worldwide who have diabetes and in 25 years that number will increase by 100 million. Although the number of people with diabetes and the cost of caring for them increases, the federal government is cutting the National Institutes of Health budget for research on diabetes. Currently, $68 per case of diabetes is spent compared to $16,936 per case of someone with West Nile Virus, which is much less prevalent (Ho, 2006).

COMPLICATIONS AND CAUSES OF DIABETES

Diabetes can lead to serious complications, such as blindness, kidney damage and lower-limb amputations. Heart disease is the leading cause of death for those with diabetes, and the risk for stroke is 2 to 4 times higher. Type 2 diabetes accounts for 90 to 95% of all diagnosed cases of diabetes, with increasing cases being diagnosed in children and adolescents (Centers for Disease Control and Prevention, 2003). Obesity is a rising cause of diabetes. A study conducted by End-Stage Renal Disease (ESRD) Network 6 found that out of 25,883 incident patients with ESRD in Georgia, North Carolina, and South Carolina, 23% reported a family history of ESRD. Of those patients with a family history of ESRD, 28% were overweight, 17.3% were obese, and 16.7% were morbidly obese. The study suggested that management of obesity is especially important for those with a family history of ESRD (Speckman et al., 2006).

Lower-limb amputation is one major complication of diabetes. It can be especially stressful for patients and health care staff. A study of 3,272 incident hemodialysis patients over a 4-year period found that diabetes, cardiovascular co-morbidity, and hemodialysis inadequacy were risk factors for lower-limb amputation (Speckman et al., 2004).

DATA FROM DOPPS

DOPPS is a longitudinal study of people on hemodialysis and unit practices. The first phase, DOPPS I (1997–2001), included data from patients in France, Germany, Italy, Japan, Spain, the United Kingdom, and the United States. DOPPS II (2002–2004) added Australia, New Zealand, Belgium, Canada, and Sweden. The goal of DOPPS was to identify practice patterns that improve patient outcomes. The major outcomes reviewed were mortality, hospitalization, vascular access, and quality of life.

U.S. patients in DOPPS were slightly older than those in Europe or Japan and had the highest prevalence of diabetes, coronary artery disease, congestive heart failure, peripheral vascular disease, and cerebrovascular disease. Older age and co-morbidities, such as diabetes, were also shown to put patients at an increased risk of mortality (Goodkin et al., 2004). For patients with at least one hospitalization, 42.7% had diabetes (Lopes et al., 2004). Additionally, nearly all (more than 90%) retinopathy and blindness complications occurred in patients with diabetes (Kaur et al., 2003). Limb amputation was also analyzed using data from DOPPS I and II. The prevalence of amputation was 6% overall, from less than 2% in Japan to 10% in the United States, with a ninefold higher prevalence in people with diabetes versus without. The majority (91%) of amputations were due to peripheral vascular disease (Combe et al., 2005).

What impact did practice patterns and care process show in DOPPS research? Analyses from the U.S. DOPPS I data was conducted by randomly selecting patients from representative dialysis facilities. A total of 4,127 patients with diabetes were reviewed. Ninety-one percent of the dialysis facilities included diabetes practices, which were defined as use of a diabetes protocol, glucose monitoring by a dietitian, or regular measurement of HbA1C. Patients in the study had a high percentage of diabetic complications (78.9% with cardiac history, 24.7% with cerebrovascular disease, 38.1% with peripheral vascular disease, 28.1% with diabetic gastroparesis, and 49.4% with diabetic retinopathy). These diabetes practice patterns demonstrated a 46% lower risk of developing diabetic foot disease. Having a primary care physician in addition to standard nephrologist care was associated with a 12% lower mortality risk. Although variations in diabetes practices were found, when they were implemented there was an associated reduction in the risk of complications and mortality (Ramirez et al., 2005).

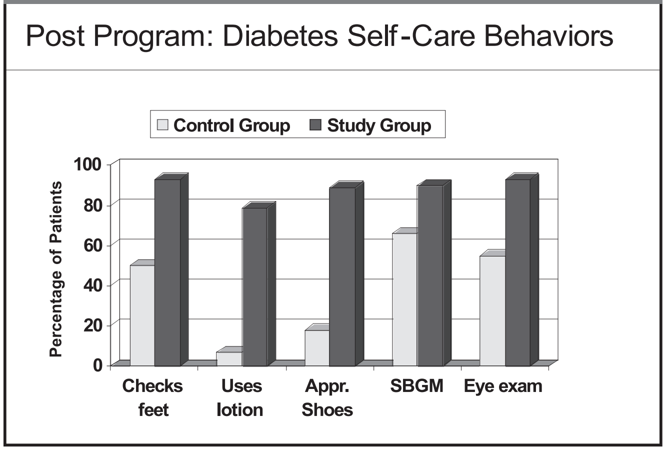
IMPLICATIONS FOR PRACTICE

The combination of the rising number of people with CKD who have diabetes and published research results identifying the mortality risks and complications associated with diabetes has resulted in some innovative programs showing some positive steps toward improving patient outcomes. A structured treatment and teaching program in a German hospital conducted since 1996 focusing on patients with type 2 diabetes demonstrated that patients who received the program had significantly better results 6 months following the program in their ability to self-manage their diabetes. Even those patients who had some impaired cognitive function showed improvement. Because of the presence of impaired cognitive function, the teaching program relied less on theory and more on practical exercises. A lower number of patients also required help from others following the teaching program than before (Schiel et al., 2004).

A 1-year diabetes management study conducted in Northeast Indiana dialysis clinics with 83 dialysis patients studied the differences in patient outcomes between a control group and a study group of patients who received intensive education and were followed by a diabetes care manager. The care manager provided self-management education, diabetes self-care monitoring and management, motivational coaching, and foot checks. Results demonstrated a number of significant differences between both groups and improvements in the study group. There were no amputations in the study group versus five amputations in the control group. Ten patients in the control group were hospitalized with diabetes- or vascular-related admissions versus one patient in the study group. Diabetes-related quality-of-life scores in the study group increased as well as self-management behaviors. Table 1 illustrates the comparison of control versus study group compliance at the end of the program with checking feet, using lotion on the feet, wearing appropriate shoes, self-blood glucose monitoring, and annual eye exams (McMurray et al., 2002).

Table 1

Self-Care Behaviors



SPECIFIC IMPLICATIONS FOR SOCIAL WORK PRACTICE

Social workers can assist patients with diabetes by helping them access needed resources and encouraging them to be compliant with their treatment requirements. Education should be provided to all new patients about Medicare or other private insurance coverage of diabetic supplies, including Medicare Part D insulin coverage. Barriers to accessing needed supplies or attending physician appointments, eye exams, etc., should be explored.

Compliance of blood sugar testing is a common problem with many patients complaining of the pain involved in the procedure. Despite new advances in less painful techniques and noninvasive monitoring methods on the horizon, painful needles may not be the main issue. It could be the cost of supplies, or just the fact that patients may have other problems they need to deal with before they can focus on their diabetes care. Laura Jones, MSW, LGSW, a social worker who works in a community health care diabetes clinic, states, "...if you do not address what the individual with diabetes considers to be the number 1 issue, you will be unable to eventually move down the list and address the diabetes...Try managing your diabetes when you are eating at the soup kitchen...Try managing your diabetes when you are without shelter and living on the street or when you are at a homeless shelter." Jones also mentions people being reluctant to work with their employers for appropriate breaks or meal times to manage their diabetes requirements (Newfield, 2006). In addition to some of the barriers Jones listed, dialysis patients also have the requirements of following their dialysis treatment requirements and diet. Social workers can assess patients' needs and, by helping them work on issues that may be completely unrelated, take care of concerns that inhibit patients from being able to focus on taking care of themselves properly.

NATIONAL KIDNEY FOUNDATION NEW GUIDELINES FOR DIABETES AND CKD

In response to the underdiagnosis of both diabetes and CKD that leads to kidney disease progression, the National Kidney Foundation (NKF) presented the new Kidney Disease Outcomes Quality Initiative (KDOQI) Clinical Practice Guidelines for Diabetes and CKD at the NKF 2006 Spring Clinical Meetings. The Guidelines include recommendations on the process for screening and diagnosing diabetic kidney disease, managing diabetes and CKD (including hyperglycemia and general diabetes care, hypertension, dyslipidemia, and nutrition), the impact of diabetes and CKD in special populations, the importance of behavioral self-management, and the value of intensive multifaceted interventions.

CONCLUSION

Because diabetes is the leading cause of chronic kidney disease and is also a national health concern that costs billions of dollars each year, more attention is being given to diagnosing, managing, and treating this disease. Research from DOPPS and other studies confirms that patients with diabetes are at increased risk for mortality and hospitalization. Innovative programs have been tested and shown to result in positive outcomes in decreasing hospitalizations and lower-limb amputations and an increase in self-management behaviors of patients. Social workers can help in the effort by educating patients on available resources, helping to obtain resources, and working with patients on psychosocial barriers to compliance. The NKF's new KDOQI Guidelines on diabetes will help encourage a standard of care for treating diabetes and helping patients manage their disease.

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Withdrawal from Dialysis: The Literature, DOPPS, and Implications for Practice

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Summary: Withdrawal from dialysis is a common occurrence in the United States, although withdrawal rates vary throughout the world. DOPPS data focusing on withdrawal and the similarities and differences among various countries are reported. Literature related to withdrawal is explored and includes the decision-making process, the reasons underlying the decision, patient characteristics, and the dying experience. Finally, practice suggestions to enhance the delivery of care during the decision-making process and at end of life are offered.

INTRODUCTION

According to the U.S. Renal Data System (USRDS) 2005 Annual Data Report, there were 324,826 individuals receiving dialysis therapy in the United States at the conclusion of 2003. During that same year, slightly more than 100,000 new individuals began dialysis, while approximately 69,000 people who were on dialysis expired. Although there are a multitude of causes of death, 22% (14,352) resulted from dialysis withdrawal during 2001 to 2002. In addition, Tigert et al. (2005) reported that 56.6% of people on hemodialysis in their study had considered withdrawal at one time.

The number of patients who withdraw from dialysis in the United States is increasing. The USRDS 1996 Annual Data Report showed that 17.6% of dialysis deaths from 1991 to 1993 resulted from dialysis withdrawal, and that percentage has steadily increased over the past decade. This increase underscores the importance of understanding the factors associated with dialysis withdrawal. This knowledge will aid caregivers in assessing those at risk for treatment withdrawal and in assuring that those individuals receive compassionate, competent care both during the difficult decision-making process and at the end of their lives.

BACKGROUND

There are existing legal and ethical principles that support a person's right to make a decision to withdraw medical treatment. The Renal Physicians Association (RPA) and American Society of Nephrology (ASN) document "Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis" (2000) highlighted these principles: patient autonomy or self-determination, justice, beneficence, nonmaleficence, and the right to make an informed decision to refuse treatment. The Patient Self-Determination Act of 1990 established the legal right of competent individuals to determine their own health care decisions and to appoint a durable power of attorney for health care to make decisions for them if they are mentally unable to do so. Although the number of Americans who have formally completed advance care planning documents is low (Emanuel et al., 1991; LaPuma et al., 1991), many individuals have exercised their right to make treatment decisions. McCloskey (1991) reported that the American Hospital Association estimated that approximately 70% of all deaths in the United States occurred as a result of withdrawal or withholding of medical treatment.

Neu and Kjellstrand (1986) reported that physicians were more likely to initiate the decision-making process that resulted in termination of dialysis for both competent and incompetent patients (66%) in the 1970s, whereas dialysis patients and/or their family members were more likely to initiate the process (70%) in the 1980s. This trend toward increased patient and family involvement has continued. Sekkarie and Moss (1998) documented that 63% of the subjects in their study had decision-making capacity and that only 14% of withdrawal discussions were initiated by the physician in such cases. However, when the person lacked capacity, these discussions were initiated by nephrologists 62% of the time.

A wealth of data (Kelner et al., 1993; Emanuel & Emanuel, 1992; LaPuma et al., 1993; Mower & Baraff, 1993) has documented that physicians do not routinely honor advance directive instructions. However, dialysis withdrawal appears to be an area in which physicians are more inclined to follow a patient's wishes, especially if the patient has decision-making capacity. Singer and the End-Stage Renal Disease Network (ESRD) of New England (1992) found that 88% of nephrologists in their study would respect a competent individual's request to withdraw from dialysis. Although 90% of these same physicians would honor family members' requests to withdraw dialysis from incapacitated patients if patients' wishes were clear, only 63% would do so if they were not. The RPA and ASN (2000) reported that nephrologists' decisions about treatment withdrawal were impacted by patient age, neurological status, comorbid conditions, physical functioning, and by family request. Other factors that affected nephrologists' decisions to withdraw dialysis were medical benefit and quality of life (Rutecki et al., 1997).

According to Singer and the ESRD of New England (1991), nephrologists reported that social workers participated in the decision to withdraw from dialysis in 95% of withdrawal cases. They were the team member assessed as the most frequently involved, followed by the primary physician and primary nurse. Ethics committee consultation was sought in less than 15% of withdrawal situations. This may be attributable to the fact that freestanding dialysis facilities having minimal access to ethics committees.

Dialysis treatments may be withdrawn for a variety of reasons. The USRDS 2005 Annual Data Report lists failure to thrive, which typically includes symptoms of decline in function, depression, and/or dementia as the cause of 42.9% of withdrawals. This cause is followed by the categories of acute medical complications and "other."

An earlier study by Neu and Kjellstrand (1986) found that the mean duration of treatment prior to dialysis withdrawal was 30 months, with 10% of the study population withdrawing after 3 years and 3% withdrawing after 9 years. A later study by Cohen et al. (1995) documented that the mean duration of treatment prior to withdrawal for their dialysis population was 43.6 months. Leggat et al. (1997a) found that patient age may play a factor (i.e., patients 65 or older were more likely to withdraw from dialysis during their third month of treatment).

Multiple research studies have explored dialysis patient characteristics that are associated with withdrawal. Past research (Leggat et al., 1997a, 1997b) has shown that Caucasians are more likely to withdraw than other races, as are females versus males. While Cohen et al. (2002) reported that most individuals who elected to discontinue dialysis did not appear to be affected by major depression, McDade-Montez et al. (2006) found that depression was a highly predictive risk factor ($P < 0.05$). Bajwa et al. (1996) reported that those who were widowed or divorced were more likely to stop treatment than those who were married. Living situation may also be associated with withdrawal decisions; Sekkarie et al. (1998) found that patients who resided in nursing homes were more likely to withdraw from dialysis. Elderly patients, who may be more likely to lack significant others or to be nursing home residents, were also more likely to withdraw, according to Cohen et al. (2000). The mean age at time of withdrawal was approximately 74 (USRDS, 2005), with the withdrawal rate beginning to increase after age 50 (Leggat et al., 1997a). Bajwa et al. (1996) found that individuals with comorbidities were twice as likely to withdraw from dialysis. Diabetes was a comorbidity associated with withdrawal (Leggat et al., 1997a, 1997b). Terminally ill patients were also more likely to discontinue dialysis (Conneen et al., 1998). Leggat et al. (1997a) found that patients who had a chronic rather than an acute health problem were much more likely to withdraw from dialysis. They also reported that individuals dying of dementia were more than four times likely to discontinue dialysis than those dying of other causes. Research by Bajwa et al. (1996) documented that a low score on the Karnofsky Performance Scale, a staff-reported subjective assessment of patient physical functioning, and spending less time outdoors were additional factors associated with increased likelihood of dialysis withdrawal. It could be assumed that those who are depressed or have poor physical functioning may also be more likely to spend time indoors and be less active overall. Leggat et al. (1997a) found that individuals on hemodialysis who performed their own treatment either at home or in a facility had a 27% higher likelihood of withdrawing from dialysis than those who depended on staff for their treatment. Patients who performed any type of peritoneal dialysis were at no greater risk of withdrawal than those who dialyzed conventionally in a facility.

The USRDS 2005 Annual Data Report documented that, overall, individuals who withdrew from dialysis were more likely (49.2%) to expire in the hospital than at home (25.3%). Approximately 42% of those who withdrew used hospice prior to their death, with 10.1 mean days of hospice services. Patients who used hospice were twice as likely to die at home (45.3%) as in the hospital (22.5%), whereas 68.5% of patients who were not involved with hospice after withdrawal expired in the hospital.

If dialysis treatment had been terminated because of medical deterioration associated with a progressive, chronic disease, Cohen et al. (1995) found that a multidisciplinary team was more likely to view a patient's death as "good," as assessed by the length of the dying experience, the discomfort experienced during the dying process, and the patient's psychological and social situation. According to Cohen et al. (2000), patients and families characterized a good death as a short, pain-free, peaceful dying process. Of patients who died after stopping dialysis, 85% were evaluated as having had either a very good or good death. Families indicated that 81% of patients did not suffer in the last 24 hours of their lives. Although pain was identified as the most common symptom after dialysis withdrawal, it was assessed as being severe in only 5% of cases. Cohen et al. (1995) suggested that dialysis patients' dying experiences could be enhanced by decreased suffering and delirium and improved pain control if they were offered appropriate palliative care.

DIALYSIS OUTCOMES PRACTICE PATTERNS STUDY (DOPPS) FINDINGS ON WITHDRAWAL

DOPPS is an international, longitudinal study that focuses on the impact of clinical practice patterns on hemodialysis patient outcomes (University Renal Research and Education Association, 2002). Phase I of DOPPS began in 1998 and involved seven countries: France, Germany, Italy, Japan, Spain, the United Kingdom, and the United States. In 2002, DOPPS was expanded and began data collection under Phase II in six additional countries: Australia, Belgium, Canada, New Zealand, and Sweden. DOPPS provides the opportunity to compare practice patterns, such as hemodialysis withdrawal rates, across countries. Termination of dialysis, compared with the other issues studied by DOPPS, may be particularly influenced by the cultural and religious values, beliefs, and practices of individual countries.

Fissell et al. (2005) conducted a study of 8,615 adult hemodialysis patients, representing 304 dialysis facilities, which were randomly selected from DOPPS I data. The number of hemodialysis treatment withdrawals per 100 patient-years of observation was used to determine withdrawal rates. The unadjusted rate of withdrawal was 1.9, with the Unites States reporting the highest rate and Germany and Italy having the lowest rates other than Japan, which reported no dialysis withdrawals. Approximately 79% of the study population expired within 10 days of terminating dialysis. The average person lived 7.8 days after withdrawal.

Those at higher risk of withdrawing were older and non-black ($P < 0.0001$ for each). Comorbidities that were associated with withdrawal were any type of cancer other than skin cancer, HIV/AIDS, coronary artery disease, cardiovascular disease, and psychiatric illness. There was a 9% lower adjusted risk of withdrawal from dialysis per 3-point higher score on both the physical and mental component summaries of health-related quality of life summary measures ($P < 0.0001$). Although not highly significant, individuals who had less than 12 years of education were more likely to withdraw from dialysis ($P = 0.06$). Patient living situation and income were not associated with an increased risk of withdrawal.

Of the 8,615 patients, 326 (38%) had a do not resuscitate (DNR) order. When patients had DNR orders, the relative risk of dialysis withdrawal was significantly higher than for individuals who did not have DNR orders ($P < 0.001$). Non-blacks and females were more likely to have DNR orders. Those with congestive heart failure, cardiovascular disease, and cancer other than skin cancer were also more likely to have DNR orders ($P = 0.06$). Patients with higher adjusted odds of having DNR orders resided in nursing homes rather than with friends or family ($P = 0.003$) and had incomes greater than $75,000 (in U.S. currency; $P = 0.06$). Educational level was not associated with having a DNR order.

Another analysis using DOPPS II data by Kerr et al. (2005) found that Japan and Germany each had the lowest dialysis withdrawal rate (2 per 100 patient-years) compared with Belgium, which had the highest (9 per 100 patient-years). They found that being black, male, or having hypertension resulted in a reduced likelihood of withdrawal. Other factors that were not significantly associated with withdrawal were pulmonary disease, diabetes, coronary artery disease, cardiovascular disease, or reoccurring gangrene or cellulitis. Those significantly more likely to terminate dialysis were older, had congestive heart failure, peripheral vascular disease, cancer, HIV/AIDS, neurological disease, gastrointestinal bleeding, a recent reduction in serum albumin or psychiatric disease. Failure to thrive was the strongest predictor of withdrawal. The data also documented that new events such as being diagnosed with cancer or having a cerebral vascular accident or myocardial infarction predicted dialysis withdrawal.

Lambie et al. (2006) used DOPPS I data from 20 dialysis units in France, Italy, Spain and the United Kingdom, 21 units in Germany, and 141 units in the United States to study the associations between practice patterns relating to initiating and withdrawing dialysis and nephrologists' opinions and patient characteristics. They also conducted a subanalysis of data in DOPPS II from corresponding units. Medical director and nurse manager responses from questionnaires about their practice patterns were analyzed to obtain further information.

Nurse managers were less likely than physicians to encourage, assist, or allow patients to withdraw from dialysis. Not surprisingly, units had lower rates of withdrawal (0.8 per 100 patient-years) in which physicians did not encourage termination of dialysis than did those in which physicians encouraged or were neutral about withdrawal (1.4 per 100 patient-years). Similarly, if physicians agreed to allow patients to withdraw from dialysis at their request, there was a higher relative risk of withdrawal than when physicians did not agree or were neutral about granting patient requests.

Nephrologists and nurse managers in the United Kingdom and the United States were significantly more likely to agree to patient withdrawal from treatment than were their counterparts in other countries. Physicians were also asked to respond to the statement, "We attempt to initiate dialysis on almost every patient with advanced renal failure, regardless of age, other medical problems, or degree of independence." The majority of physicians in the United Kingdom either strongly disagreed or disagreed with the statement and those in the United States responded neutrally, while the physicians in the other countries either agreed or strongly agreed.

Nephrologists in the United Kingdom, the United States, and France reported they were more likely to maintain a waiting list for patients to initiate dialysis, had delays in beginning hemodialysis, and were more likely to start patients on other treatment modalities such as peritoneal dialysis because hemodialysis units were at capacity. It was speculated that this may have influenced the willingness of U.K. and U.S. physicians to more readily consider withdrawal as an option.

Lopes et al. (2004) analyzed DOPPS II data from 12 countries for 9,382 people on hemodialysis specifically assessing associations correlated with depression. Although depression has been identified as the most common psychological problem experienced by individuals on hemodialysis, there is speculation that it may also be underdiagnosed and undertreated among this population. They found that physicians were more likely to diagnose depression in patients in Sweden, followed by the United States, with Japan having the lowest physician diagnosis rate. However, when patients completed the Center for Epidemiological Studies Depression (CES-D) screening index, 43% had scores of 10 or higher (indicating symptoms of depression) compared with 13.9% who had a physician diagnosis of depression. Using the scores from the CES-D, Japan's rate of depression was similar to the overall prevalence rate of 43%. Overall, females, unemployed individuals, those with lower levels of serum albumin, and patients with congestive heart failure, peripheral vascular disease, lung disease, neurological disease, or gastrointestinal bleeding were significantly more likely to be diagnosed as depressed, using both measures of depression. Antidepressants were more likely to be prescribed if physicians diagnosed the depression than when patients were diagnosed as depressed, according to their responses on the CES-D. Swedish patients (52.8%), followed by Canadian patients (44.1%), were more likely to be prescribed antidepressants when physicians diagnosed the depression. Patients in the United States who scored 10 or higher on the CES-D (28.9%) were the most likely to be prescribed antidepressants, followed by Swedish patients (28.8%).

Even when adjusted for age, sex, socioeconomic factors, length of time on dialysis, and country, there was a 55% higher relative rate of dialysis withdrawal for patients who scored 10 or higher on the CES-D. When physicians diagnosed depression, there was also an independent and significant association with a higher relative risk of dialysis termination.

Kurella et al. (2006) analyzed DOPPS data from 16,694 people on hemodialysis in an attempt to determine correlates and outcomes of dementia. Four percent of their study population had been diagnosed as having dementia. Age, black race, low educational level, malnutrition, anemia, diabetes, and cardiovascular disease were all independent risk factors for dementia. Dementia was associated with an increased risk of both death and withdrawal from dialysis.

IMPLICATIONS FOR PRACTICE

Treatment withdrawal has received considerable attention not only from the American public and general medical community but also within the field of chronic kidney disease. Documents on withdrawal from dialysis have been developed by the National Kidney Foundation (NKF), as well as by the RPA and ASN. Both documents are intended to provide guidance to dialysis professionals as they address the issue of treatment withdrawal with their patients and family members.

The NKF document "Initiation and Withdrawal of Dialysis in End Stage Renal Disease: Guidelines for the Health Care Team" (1996), is a consensus statement that was based primarily on expert opinion. It specifies that the patient's values, preferences, and goals should be major factors in deciding whether to terminate dialysis. The health care team should be involved in the decision-making process by offering medical, educational, and emotional support to patients (and their families or surrogates, if applicable). However, if individuals are competent to make their own health care decisions, the final decision about whether to terminate dialysis should ultimately be theirs.

When a patient expresses a desire to terminate dialysis, it is suggested that the health care team first assess whether the patient is competent to make the decision. If the patient is not competent and has a durable power of attorney for health care, that person is responsible for the decision. If no one has been appointed to act in this capacity, the health care team has the responsibility to determine who has the legal right to act on behalf of the patient. Once competency has been determined, the document clarifies that the health care team's role is to assess the factors underlying the patient's or surrogate's decision to stop dialysis. If appropriate, interventions should be initiated to attempt to deal with the identified issues.

The document suggests that if there is disagreement or uncertainty about the benefits and burdens of dialysis, treatment should be continued for a 30-day period, at which time there should be re-evaluation of the situation by the health care team, including the patient or the surrogate as an active member. After the 30-day period, a recommendation should be presented to the patient or surrogate, with the final decision about whether to continue dialysis ultimately being his or hers. The document recognizes physician rights to refuse to provide treatment that is determined to be futile. However, mandatory withdrawal standards based on such factors as age, life expectancy, quality of life, or intellectual or physical functioning were rejected.

The guidelines specify that the health care team has continued responsibilities if patients elect to withdraw. Education about what to expect during the course of dying is imperative. In addition, the team must assure that bereavement counseling is offered. Where and how patients desire to die should be determined, with preferences honored when possible. The document also stresses that it is imperative that patients understand that the decision to terminate dialysis is reversible. It concludes by specifying that the facility should anticipate and address staff issues that may arise as a result of patient withdrawal from dialysis. These may include such feelings as anxiety, guilt, sadness, and grief.

The RPA/ASN document, "Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis" (2000), is a clinical practice guideline based on both a systematic literature review and expert opinion. Its ultimate goal is to promote shared decision-making in the patient–physician relationship around the issue of withdrawal from dialysis. Informed decisions and full disclosure are integral components of shared decision making.

This clinical practice guideline states that it is appropriate to withdraw dialysis from patients who have decision-making capacity, are informed, and make a voluntary choice. The importance of assessing patients for depression and other psychiatric problems during this process is stressed. Withdrawal is also appropriate when a person no longer has capacity and has either indicated previously in an advance directive that dialysis should be stopped in this circumstance or when the person's legal agent requests dialysis termination. Finally, withdrawal is acceptable if a patient has irreversible, profound neurological impairment, lacking signs of thought, sensation, purposeful behavior, and awareness of self and the environment. These guidelines further elaborate that it is reasonable to consider withdrawal if a patient has a terminal illness due to a non-renal cause with a life expectancy of less than 6 months and is not a candidate for organ transplantation. Other reasons that withdrawal should be considered include: having medical conditions that interfere with the performance of dialysis; an irreversible inability to relate to others in a purposeful manner; significant, ongoing access problems; failure to thrive; and inability to cooperate with dialysis. There is clarification that nonadherence with the medical regimen is not a reason for staff to consider withdrawing dialysis.

As with the NKF document, the RPA/ASN guidelines also suggest a time-limited dialysis trial if there is uncertainty about the prognosis or if there is a lack of consensus on how to proceed. This trial of approximately 1 to 3 months may offer patients and their families an enhanced understanding of dialysis and its benefits or burdens. It may also provide the team with a more informed assessment of the likelihood of the benefits of dialysis outweighing its burdens for the individual. Ultimately, a trial period of dialysis can further promote shared decision making.

The document stresses that while palliative care should be offered to all patients throughout the course of their illness, everyone who withdraws from dialysis should be offered this type of care. It should include pain and other symptom management, attention to psychosocial and spiritual concerns, and identifying and addressing what matters most to the individual during the dying process. Bereavement support should also be made available.

Beyond these guideline documents, there are additional issues, such as when to discuss withdrawal from dialysis, that should be addressed. When individuals begin dialysis, they should be offered every treatment option—center and home hemodialysis, peritoneal dialysis, and kidney transplantation—for which they are medically suited. In addition, they should be offered the option of not beginning dialysis. They should be informed that even if they elect to initiate dialysis, the option of withdrawing from dialysis remains available to them at any time should they decide the burdens of dialysis outweigh the benefits. Discussing withdrawal early on gives patients "permission" to discuss it with the health care team in the future should the need arise. In one study, 19% of patients were not aware they could terminate dialysis and 92% had never been approached about this issue by their nephrologists (Leggat et al., 1997b).

Social workers are often involved with patients who elect to withdraw from treatment. As a result, social workers, as well as all dialysis team members who deal with the issues of death and dying, must be aware of their own feelings and values related to patient withdrawal from dialysis and death. This awareness assists staff members in not transferring their values and beliefs about these subjects onto patients, and thus unduly influencing their decisions. If any staff members are unable to deal with patients around these issues in an objective, supportive manner, it is their responsibility to refer patients to others who are able to do so.

If a patient is contemplating termination of dialysis, one of the social worker's main roles is to conduct a thorough psychosocial assessment of factors underlying the consideration. Changes that have occurred in the patient's physical or mental health status, family situation, social or vocational environment, finances, or quality of life, as well as current stressors should be considered. Factors known to be associated with dialysis withdrawal should be assessed to determine whether they might be contributors to the specific patient situation. Although patients have a right to self-determination, they also have the right to be informed about interventions that may have an impact on their unique situation and, ultimately, their decision to withdraw from life-sustaining treatment.

Dialysis withdrawal should not automatically lead to the conclusion that a patient is depressed or suicidal, although the literature supports that depressed patients are more likely to withdraw from dialysis. If a patient is determined to be depressed, it is appropriate to discuss psychotherapy or antidepressant medications that may be beneficial. If unacceptably decreased physical functioning or increasing dependence is contributing to a patient's decision to terminate dialysis treatment, an intervention such as physical and/or occupational therapy may be appropriate. Because individuals who have reduced social support, such as those who are widowed or divorced, are more likely to withdraw, attempts to expand their support network through extended family, friends, support groups, or other activities may be beneficial.

Just as patients have a right to learn of possible therapeutic interventions that might affect their decisions about withdrawal, they also have a right to have accurate information upon which to base their decision. Patients may struggle with whether terminating a life-saving treatment such as dialysis is considered suicide. Approximately 12% of dialysis patients in the study by Cohen et al. (2002) were either uncertain or believed that stopping dialysis equated with suicide. Although this decision must be made by the individual, it may assist the patient to know that according to the NKF (1996) document, Western ethical and most religious traditions recognize a person's right to terminate heroic or aggressive medical treatment that delays the dying process. Staff should also be prepared to provide information on such issues as whether patients should continue with dietary, fluid and medication regimens, if death after withdrawal is painful, and regarding life expectancy without dialysis treatment. Typically, patients are advised to avoid fluid overload that could lead to pulmonary distress. In their study, Cohen et al. (2000) found that nonpalliative, unnecessary medications and laboratory tests were stopped for most patients who decided to terminate dialysis. The same study reported that 85% of deceased dialysis patients' families rated the dying experience of patients who had withdrawn from dialysis as either very good or good, with a "good" death being described as having no pain, being at peace, and of short duration. Death from dialysis termination also typically involves an increased lack of consciousness due to uremia. Sekkarie et al. (1998) reported that the mean number of days post-withdrawal from dialysis until the time of death in their study was 12 days, while others (Cohen et al., 2000) found that the mean rate was 8.2 days. It is important for patients to be aware of the average length of survival after stopping dialysis to allow them to appropriately plan for their final days.

The NKF guidelines state that patients and their families should have assistance in preparing for death after dialysis withdrawal. Social workers can play an important role in this preparation. It should be suggested to patients that completing both a living will and appointing a durable power of attorney for health care, if they have not already done so, may help assure that their final wishes are carried out. Patients should also be encouraged to complete a will for distribution of their financial assets and personal items. If appropriate, organ and tissue donation should be explored. Patients should be asked if they desire support from a religious or spiritual advisor during this time. The idea of making an audio or videotape or writing letters to family and friends to allow for expression of their feelings and sharing their thoughts should be suggested. It is also important to determine where and how patients desire to die. The social worker may assist by arranging medical equipment, home health care, and/or hospice services, if appropriate. Hospice services are underutilized by dialysis patients, as the USRDS 2005 Annual Data Report points out. Only 41.9% of those who withdrew from dialysis had hospice care during 2001 to 2002. Additionally, family members need to be informed in advance about the protocol to follow if patients expire at home. Patients may also want to consider their preferences for a funeral or memorial service.

It is important for dialysis staff to realize the important role they have played in the lives of their patients and family members and understand that it is crucial that they not abandon them during this critical period. Although patients will no longer be receiving dialysis treatment at the facility, the social worker and other staff who have played major roles in providing care should maintain contact with both patients and their families during the dying process to offer them the opportunity to deal with unfinished issues, have questions answered, and either provide counseling or refer them to counseling resources. Families should also be informed of bereavement support that is available after patients expire. The social worker should consider contacting family members to offer support at certain times, such as the 6-month or 1-year anniversary of the death.

Any patient death has an emotional impact on the staff and other patients in the dialysis unit. This is especially true when the death is due to dialysis withdrawal. Staff may express ambivalence, guilt, anger, or sadness. Fellow patients may feel depressed or vulnerable. Social workers can play significant roles in offering support to staff during patients' decision-making processes, as well as to both staff and patients who have been impacted by the withdrawal from treatment and the ensuing death. The Kidney End-of Life Coalition (Mid-Atlantic Renal Coalition) offers suggestions to facilitate the patient and staff grieving process that include devoting a portion of staff meetings for discussion of patient deaths; posting obituaries or funeral or memorial notices once they have become public; maintaining a journal for staff to share their feelings about expired patients; providing a sympathy card for the patient's family that staff, patients, and their family members can sign; and holding annual nondenominational memorial services that staff, patients, and families can attend.

CONCLUSION

Not only do people on dialysis have a right to know they can terminate dialysis treatment at any time, they and their families also deserve information, support, and counsel if they face such a decision. If the decision to withdraw from dialysis is made, they have a further right to expect that they will not be abandoned and will receive quality care at the end of their lives. Social workers are not only uniquely trained to play an integral role in each of these areas, it is their professional obligation to do so.

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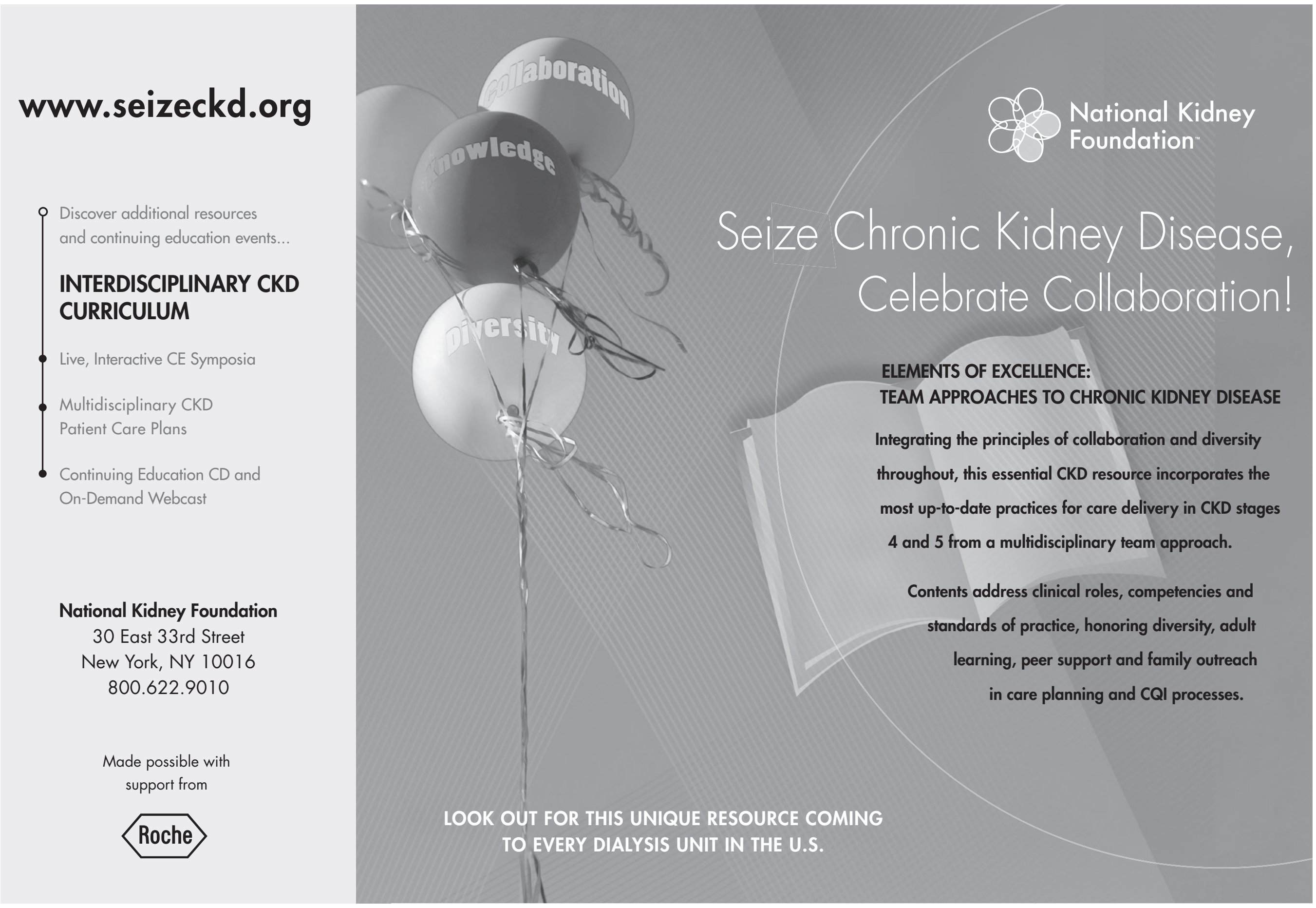

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DOPPS and the Elderly: Implications for Nephrology Social Work Practice

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Over the past three and a half decades, since Medicare funding became available for people with end-stage renal disease in the United States, the numbers of elderly on dialysis have increased dramatically and now represent well over half of the dialysis population. Beginning in the late 1970s, psychosocial issues and challenges faced by elderly people on dialysis emerged in the literature. Among other findings, these studies identified increased comorbidities and depressive symptomatology, decreased physical and mental functioning, and improved compliance. These studies were limited in size and represented either single facilities or multiple regional facilities. The Dialysis Outcomes and Practice Patterns Study (DOPPS) is an observational, longitudinal study providing a wide range of data on a sample of people on hemodialysis randomly selected from nationally representative samples of dialysis facilities in 12 countries. In the current investigation, DOPPS findings indicate that the mean age of people on hemodialysis in nearly all study countries is at least 60 years, that cardiac disease is one of the most common comorbidities, that elderly patients are at significantly greater risk for malnutrition, and that compliance with treatment schedules is significantly better in elderly people. Health-Related Quality of Life scores demonstrate that physical functioning is markedly decreased, though mental component summary scores did not decrease with age. Finally, risk of death and withdrawal from dialysis are significantly higher for the elderly. Psychosocial evaluation of the elderly and social work intervention to maximize social, psychological, mental, and physical functioning are addressed, as well as end-of-life issues.

INTRODUCTION

In the early days of dialysis, when facilities and funding sources were scarce, elderly people were not considered candidates for dialysis. In the United States, as Medicare funding became available in 1973 and resources were expanded, the numbers and percentages of elderly persons on dialysis markedly increased. By 1989, U.S. Renal Data System (1989) data indicated that patients 60 and older represented approximately 40% of the dialysis population. Less than a decade later (USRDS, 1998), the percentage of patients 60 and older had increased to 45%. In the most recent full-year data available (USRDS, 2003), patients 60 and older represented 60.7% of those on dialysis. Internationally, in data to be presented later in the Dialysis Outcomes and Practice Patterns Study (DOPPS) findings, the mean age of dialysis patients in represented countries is at least 60 years in most countries. Clearly, the increasing numbers of elderly on dialysis require ongoing investigation of the medical, physical, psychological, and social issues faced by this patient group and the identification of effective interventions to be provided by dialysis treatment teams.

BACKGROUND

Approximately three decades ago, research on the special needs of the elderly on dialysis began appearing in the literature (e.g., McKevitt & Kappel, 1978). Early findings indicated that in an urban university medical center facility, the majority of patients were white, female, and most had not completed high school. The overwhelming majority of the elderly patients on dialysis were receiving in-center treatment and were remarkably compliant in following their treatment regimens. Most patients were able to manage self-care activities, though many needed assistance with household and shopping tasks. Among areas identified by patients as needing increased attention were fear of dependency, loneliness, and depression.

In a later study (McKevitt et al., 1986), it was reported that the comorbidities of elderly persons on dialysis are highly significant. In regard to functional capacity, only 32% of patients were found to be totally independent. Compliance among older patients appeared better, with significantly better compliance if living with another adult (rather than alone). Evaluation of mental status revealed that 33% of elderly patients had mild to severe organic impairment and that the elderly experienced increased likelihood of depressive symptomatology. In regard to dialysis modality and quality of life (Nissenson et al., 1990), it was found that there are not significant differences in the quality of life associated with differences in treatment modality of older patients (i.e., continuous ambulatory peritoneal dialysis, continuous cycling peritoneal dialysis, or home or center hemodialysis). However, elderly patients were found to be more likely in need of social and other support services and that receiving these services was an important contributor to well-being.

In a follow-up study (McKevitt et al., 1990), researchers reported that the demographics of elderly patients had changed—they represented an increased portion of the dialysis population, were older, increasingly persons of color, female, and widowed, with even less education and income. In addition, there were increased comorbidities and decreased functional capacity, with three out of four patients demonstrating at least mild depressive symptomatology.

Among a series of studies (e.g., Kutner et al., 1981, 1990, 1997), it was reported that with the exception of African American women, depressive symptoms were more evident among patients aged 55 and older than among patients under age 55. It was also found that a patient's educational level was significantly related to leisure activity scores, psychological affect balance, depressive symptomatology, and perceived control over one's own health. In addition, a significant relationship with age was found for depressive symptomatology, as well as a significant relationship of patients' gender with leisure activity scores (men versus women). It was concluded that the medical challenges associated with undergoing end-stage renal disease therapy may be greater for the older patient due to additional comorbidities and age-related frailty among older persons. It was also noted that older persons are challenged by a number of psychological issues that often accompany aging, including bereavement, social isolation, loss of social status and social roles following retirement, depression and anxiety, and cognitive losses. Finally, it was reported that long-term survival in older patients on dialysis was associated with younger age and lower reports of coronary artery disease as a comorbidity. In addition, survivors had less health limitations in activity, less functional impairment, and more frequent activity and exercise.

THE DIALYSIS OUTCOMES AND PRACTICE PATTERNS STUDY

Noting that previous studies were limited in size and scope, DOPPS provides detailed information on dialysis therapy in a sample of hemodialysis patients randomly selected from nationally representative dialysis facility samples in 7 countries from 1996 to 2001, and 12 countries since 2002. As an observational, longitudinal study, the principal goal of the DOPPS is to collect data about different dialysis practice patterns and their influence on patient outcomes. In DOPPS, older patients are defined in two age groups: 65 to 74 years old and 75 years and older. The following findings compare treatment and outcomes for older chronic hemodialysis patients to those of younger patients (18 to 44 years and 45 to 64 years).

MATERIALS AND METHODS

DOPPS I data were collected from adult (18 years and older) end-stage renal disease patients receiving hemodialysis at 145 dialysis centers in the United States (from July 1996 to January 2001); 21 centers in Germany; 20 centers each in France, Italy, Spain, and the United Kingdom (from May 1998 to November 2000); and 64 centers in Japan (from February 1999 to May 2001). Study facilities were randomly selected within a stratified sampling frame to provide representation by geographic region and facility type. Within these nationally representative samples, longitudinal data were obtained from randomly selected patients. Demographic data, years on dialysis, and comorbidities, including psychiatric diagnoses, were obtained through medical record abstraction. Baseline and follow-up medical questionnaires on practice patterns were completed by each unit's medical director and study coordinator. Among other patient data collected, patients completed the Kidney Disease Quality of Life™ instrument, which includes the SF-36 health survey, to determine the mental component summary (MCS), the physical component summary (PCS), and the kidney disease component summary (KDCS).

A modified subjective global assessment (mSGA) was determined at baseline for each patient, based on caregivers' responses to questions about weight loss and physical appearance and on patient responses to questions about appetite, nausea, energy level, and disease burden. Based on this information, patients were classified into one of three mSGA categories: normal, moderately malnourished, or severely malnourished. Patient withdrawal rates were calculated as the total number of withdrawals per 100 patient-years of observation time. Noncompliance was defined as skipping one or more scheduled hemodialysis sessions in a month or shortening at least one hemodialysis treatment by 10 minutes or more in a month.

A wide range of additional data was collected on patient outcomes and practice patterns (e.g., vascular access, normalized protein catabolic rate, staffing, and others), although they will not be reported for the purposes of this article. Additional details of the DOPPS study methodology have been described by Young et al. (2000).

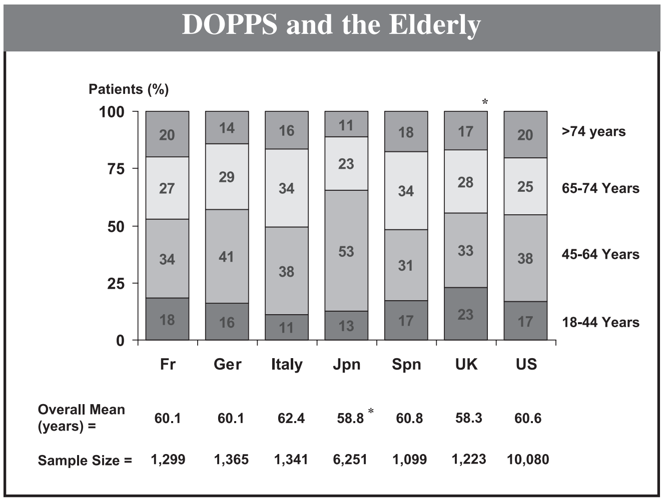
STATISTICAL METHODS

All statistical analyses were performed using SAS version 8.2 (SAS, 1999). Age distributions were calculated from the census of patients in all selected facilities present on July 1, 1999 (n = 22,803). Descriptive statistics on patient demographics, comorbid conditions, adherence, and withdrawal were calculated for the initial cross-section of prevalent patients on hemodialysis (n = 8,615). Nutritional values, laboratory values, dose, and mSGA were examined for patients who had been on hemodialysis for longer than 1 year (n = 7,932). Mortality analysis (n = 17,107) and health-related quality-of-life (HRQOL) models (n = 12,082, i.e., 71% completed the patient questionnaire) included all patients available, with an adjustment for patients in the initial round of data collection and for patients on dialysis less than 30 days. Differences in age groups, demographics, comorbid conditions, nutritional values, laboratory values, mSGA, and HRQOL by age group were examined using mixed models, which accounted for facility clustering. Patient adherence was examined using logistic regression. For the logistic regression models, generalized estimating equations were used to account for clustering at the facility level, assuming a compound symmetry covariance structure (SAS/STAT, 1999). Cox regression was used to model withdrawal and mortality rates. The sandwich estimator was used to account for facility clustering. The Cox models were stratified by country of residence, assuming nonproportional effects on death rates. As noted earlier, analyses were conducted on four different age groups. Patients were censored if they left the study for any reason other than death (such as change in modality, etc.).

RESULTS

Among the seven DOPPS countries, there were relatively small differences in the distribution of age groups in a cross-section of prevalent hemodialysis patients, except a higher prevalence in the 45 to 64 age group in Japan (53% of patients compared with 31–41% in the other six countries; Figure 1). The highest mean ages (62 years in Italy and 60.41 years in France and Germany) and the lowest mean ages (58 years in the United Kingdom and 58.8 years in Japan) were significantly different from the overall average of 60 years ($p > 0.01$).

Figure 1



Age distribution for hemodialysis patients by country. The stacked bar charts show the distribution of age groups in each country for the census of patients studying the study on July 1, 1999. Under each bar is the overall mean age by country. The overall mean age is 60 years. An asterisk indicates average ages that are significantly different from the overall mean at p < 0.05. Fr, France; Ger, Germany; Jpn, Japan; Spn, Spain.

Older patients exhibited more comorbid conditions (Table 1). For example, for a prevalent cross-section of patients, the presence of coronary artery disease and congestive heart failure increased steeply with age. The presence of coronary artery disease was more than threefold greater in patients older than 74 than in patients younger than 45 (52% versus 14.7%). The prevalence of congestive heart failure was more than twice as high in patients older than 74 than in patients younger than 45 (43.2% versus 19.8%). The portion of hemodialysis patients who were male or black declined significantly with increasing age.

Table 1. Demographics and Comorbidities by Age Category for Prevalent Patients

Measure	Patients (%)				Linear trend (per 10 years older)
	18ñ44 years	45ñ64 years	65ñ74 years	>74 years	
Demographics					
Male (%)	61.2	59.0	53.8**	51.8*	-2.1%***
Black (%)	25.5**	18.5	14.8**	12.8***	-1.8%***
BMI (kg/m^2)	23.2***	23.8	23.8	22.9***	-0.07†
Comorbid conditions (%)					
Coronary artery disease	14.7***	33.1	43.7***	52.0***	+8.0%***
Congestive heart failure	19.8***	25.2	33.9***	43.2***	+4.8%***
Other cardiac disease	18.6***	28.9	39.2***	48.7***	+6.3%***
Hypertension	73.7	71.5	74.9	74.0	+0.4%
Cerebrovascular disease	5.6***	13.2	20.7***	22.5***	+4.2%***
Peripheral vascular disease	7.1***	19.4	28.0***	29.1***	+5.0%***
Diabetes mellitus	15.7***	34.8	41.7***	31.1***	+4.3%***
Lung disease	3.8***	7.2	12.5***	15.1***	+2.4%***
Cancer (other than skin)	2.5***	6.4	10.5***	15.4***	+2.7%***
HIV/AIDS	1.9***	0.5	0.1†	0.0†	-0.4%***
GI bleed	4.1***	6.7	8.0	8.5	+1.0%***
Neurological disorder	9.9***	5.4	8.7***	13.9***	+0.7%**
Psychiatric disorder	22.1	18.6	17.9**	17.9**	-1.4%***

Reference group for all statistical comparisons = patients ages 45–64 years.
†$p < 0.05$, *$p < 0.01$, **$p < 0.001$, ***$p < 0.0001$

Table 2. Indirect Nutritional Parameters by Age for Patients > 1 Year ESRD

Measure	Patients (%)				Linear trend (per 10 years older)
	18ñ44 years	45ñ64 years	65ñ74 years	>74 years	
Malnourished (%)					
Moderately	6.8	7.2	8.4	11.1*	+0.9%†
Severely	4.4	3.8	4.9	7.8***	+1.4%***
Laboratory Measures					
Serum albumin (g/dl)	3.92†	3.84	3.76†	3.65***	-0.07***
Serum creatinine (mg/dl)	12.1***	10.6	9.3***	8.1***	-0.8***
Hemoglobin (g/dl)	10.7	10.5	10.6	10.6	-0.0
Dialysis Dose (sp Kt/V)	1.37	1.37	1.38	1.39	+0.005†
nPCR (g protein/kg body weight/day)	1.09*	1.07	1.02***	0.98***	-0.03***

Compared to patients 45-64: †$p < 0.05$, *$p < 0.01$, **$p < 0.001$, ***$p < 0.0001$.
nPCR, normalized protein catabolic rate.

For indirect measures of nutritional status, older patients were more likely to be moderately or severely malnourished (Table 2). Of patients older than 74, 11.1% were moderately malnourished compared with 6.8% of patients ages 18 to 44 and 7.8% were severely malnourished compared with 4.4% of patients ages 18 to 44. In regard to adherence, older patients skipped treatments significantly less frequently than patients ages 45 to 64 (Table 3). Shortening dialysis sessions occurred significantly more frequently in the youngest study group (ages 18 to 44). In contrast to the improved adherence of treatment with age, withdrawal from dialysis greatly increased with age (Table 3). Patient withdrawal from therapy was significantly higher at ages above 64. Particularly for patients older than 74, more than five patients per every 100 patient-years withdrew from dialysis. This trend was significant with and without adjustments for patient characteristics.

Table 3: Patient Adherence and Withdrawal Measurements, Prevalent Patients

Measure	**18–44 years**	**45–64 years**	**65–74 years**	**>74 years**
Non-adherence measures (%)				
Skipped ≥ 1 treatment per month	7.4**	3.9	2.5	2.5†
Shortened ≥ 1 treatment by 10 minutes or more per month	20.3***	11.8	9.6*	10.8†
Withdrawal				
Withdrawal/100 patient-years	0.5	0.8	2.1***	5.1***

†$p < 0.05$, *$p < 0.01$, **$p < 0.001$, ***$p < 0.0001$
(compared to patients ages 45-64)

HRQOL declined with age for the PCS, even after adjustment for demographics, comorbid conditions, and country of residence (Table 4). Patients over the age of 74 had adjusted PCS scores almost 7 points lower than patients younger than 45. In contrast, the adjusted MCS did not decrease significantly with age. Patients over age 74 had MCS scores of 44.7 while patients ages 18 to 44 had MCS scores of 44.5. In addition, as indicated by a simple summary of all kidney disease component scores from the Kidney Disease Quality of Life™, the burden of kidney disease does not affect the quality of life of elderly patients more than younger patients.

As expected, the risk of death was higher in elderly patients when stratified for country and adjusted for demographics, both with and without adjustments for comorbid conditions (Table 5). The relative risk for ages 75 and older versus 18 to 44 was 4.9, without consideration of differences in comorbidities and 3.7 (i.e., 3.7-fold higher) if comorbidities were the same for these age groups (adjusted for comorbidities), which indicates that age is a significant predictor of mortality independent of the fact that older patients have more comorbid conditions. The risk of death was more than twofold higher in patients older than 75 compared with patients ages 45 to 64.

Table 4: KDQOL-36 Summary Scores by Age Category, All Patients

KDQOL-36 Sumary Scales	**18–44 years**	**45–64 years**	**65–74 years**	**>74 years**
Physical Component Summary	39.2***	36.2	34.2***	32.5***
Mental Component Summary	44.5†	45.4	44.6	44.7
Kidney Disease Component Summary	63.1	62.7	63.3	64.9***

Adjusted for sex, race, country of residence, comorbid conditions listed in Table 1, incidence status.

†$p < 0.05$, *$p < 0.01$, **$p < 0.001$, ***$p < 0.0001$
(compared to patients ages 45-64)

Table 5: Relative Risk of Mortality by Age Category, All Patients

	Adjustments			
Age Category	Demographics*		Demographics and Comorbid Conditions**	
	Relative Risk of Mortality	p-value	Relative Risk of Mortality	p-value
18-44 Years	0.48	<0.0001	0.58	<0.0001
45-64 Years	1.00	Reference	1.00	Reference
65-74 Years	1.56	<0.0001	1.41	<0.0001
>74 Years	2.36	<0.0001	2.15	<0.0001

*Adjusted for sex, race, incident status, and stratified by country of residence.

**Also adjusted for comorbid conditions listed in Table 1.

DISCUSSION

Earlier individual and multiple dialysis facility studies in the United States (cited previously) identified increased comorbidities, mortality, and compliance in the elderly, while at the same time identifying decreased physical functioning. In addition, psychosocial issues, such as an increasingly diverse patient population, patients with limited income and education, increased evidence of depressive symptomatology, and the need for social support, were found.

On a very broad scope, DOPPS presents the first detailed information on dialysis therapy in a sample of patients on hemodialysis of all ages randomly selected from nationally representative samples of dialysis facilities in seven countries that together comprise nearly 70% of the world's hemodialysis population. In DOPPS, mortality was still higher among elderly patients when the analysis was adjusted for patient demographics and stratified by country of residence. The latter step was necessary because patients' survival differs markedly between some countries. Not only do race and general mortality differ among countries, but genetic precondition, diet, social environment, family life, religion, and a host of other factors differ as well. Therefore, different mortality rates among countries should be considered to evaluate the effect of age-related problems among elderly patients on hemodialysis.

Elderly patients are expected to have higher mortality rates because they suffer from more comorbidities. However, even after adjustment for comorbidities, mortality was still substantially higher in elderly patients. In DOPPS, patients on hemodialysis older than 75 had mortality rates more than twice as high as those of patients ages 45 to 64 ($p > 0.0001$). DOPPS data also demonstrates that the prevalence and severity of cardiac comorbidities increase mortality risk in elderly patients. Vascular problems were frequently found and their prevalence increased with the age of patients. In the group of patients older than 75, 52% had coronary artery disease, 23% had cerebrovascular disease, and 29% had peripheral vascular disease.

Serum albumin levels were significantly lower for patients ages 65 to 74 and 75 and older when compared with younger age groups (Table 2). A significantly higher percentage of elderly patients were found to be in a moderately or severely malnourished state, as measured by the mSGA. Low body mass index and serum albumin are among the strongest predictors of early death and morbidity in patients on dialysis (Leavey et al., 2001) and may contribute to the increased mortality in elderly patients on dialysis.

Reduced physical activity was indicated in elderly DOPPS patients because PCS was substantially lower with older age. The reduced physical condition accompanying hemodialysis likely limits physical activity in elderly patients. However, this does not exclude a possible benefit of exercise in elderly patients on dialysis. For example, it was reported (Moreno et al., 1996) that improvement of anemia under erythropoietin therapy resulted in a comparable increase of physical function in patients 60 and older, compared with those younger than 60. Furthermore, a pilot physical therapy consultation program (Pianta & Kutner, 1999) found that exercise regimens consistent with individual patient needs and functional difficulties could be developed and implemented for elderly patients.

Lower PCS scores of elderly patients were not mirrored by a decrease in MCS. Nonetheless, for all patients on dialysis, the incidence of depression and its significant relationship to mortality and hospitalizations has been identified in DOPPS (Lopes et al., 2002). In addition, the KDCS was comparable in younger and older patients, indicating that elderly patients do not suffer more from kidney disease burden in comparison to younger patients. Whether this can be attributed to differing age-related expectations and life cycle stages (e.g., for the elderly, demands of raising children, dealing with vocational and employment issues, etc., are generally moot) is interesting to speculate.

Finally, despite the results in the MCS and KDCS scores, the rate of patient withdrawal from hemodialysis increased with age and was fivefold higher for patients 75 and older compared with the reference group (ages 45 to 64). The reasons for this difference in withdrawal rates were not determined in this study, although it has been reported elsewhere (Leggat et al., 1997a) that nearly 50% of withdrawals were preceded by an acute medical complication, while the remainder followed a chronic decline. Additional detailed prospective data collection is needed regarding psychological, social, economic, ethical, religious, and other factors that may contribute to the higher rate of withdrawal from dialysis.

IMPLICATIONS FOR SOCIAL WORK PRACTICE

Managing the many challenges faced by elderly patients on dialysis is, undoubtedly, a multidisciplinary effort requiring various levels of coordination between physicians (nephrologists, diabetologists, vascular surgeons, cardiologists, and rheumatologists, among others), pharmacists, dietitians, nurses, and social workers. Protocols to manage adequacy of dialysis, hypertension, anemia, bone disease, depression, and diabetes, for example, and referrals to specialty services are among the essential issues addressed in the care of patients on dialysis. Recognizing and addressing the physical and psychological demands of that care and the effects of aging on physical and psychological functioning are essential in caring for elderly patients. This is the arena in which nephrology social workers focus their efforts.

Because health care systems and funding, cultural factors, and availability of community resources and services vary from country to country, for the purposes of this article, the following assessment and intervention strategies are presented relative to elderly patients in the United States.

The first step in planning social work intervention is always a comprehensive assessment and this is essential in working with elderly persons on dialysis. Five key areas for evaluation are presented in the following sections.

Social Issues

Living situation: Is the patient living independently, with a partner, family member, etc.? Is the living situation adequate and appropriate for the patient's needs/limitations? Is the housing safe, accessible, and affordable?

Support system: Is there adequate support to meet the patient's needs for supervision and/or assistance? Who is available for emergency assistance? Are personal aide and/or homemaker services needed? Is the patient a major source of support and care for a spouse, disabled adult child, grandchildren, etc.?

Social needs and meaningful activities: What social outlets does the patient have? Is the patient involved in family, social, senior, community, exercise, or church activities? Does the patient have particular hobbies or interests? Have previous activities declined as the patient's functional status changes? What modifications or adaptations might be made for the patient to resume or continue meaningful and enjoyable activities?

Income: What are the sources of income? Is income adequate to meet needs? Are all possible income sources in place? Are there significant financial stresses or debt? Based on income, might the patient be eligible for additional federal, state, and/or voluntary agency programs?

Health care coverage: Is current coverage adequate and affordable? Are all available health care benefits in place? Are medications covered? What are the copays and are they affordable? Are such benefits as home services, nutritional supplements, and assistive devices included in the coverage?

Transportation: Does the patient have a safe, affordable transportation plan? Are special services needed, such as wheelchair transport? Is the patient eligible for special services? What is the patient's transportation backup plan?

Health Care and Compliance Issues

Comorbidities: What medical diagnoses other than chronic kidney disease does the patient have? What are the implications for obtaining and coordinating care with other medical and hospital services? How do other medical problems impact functional status? Is the patient/support system able to manage the demands and limitations of other medical problems and treatment?

Compliance: What is the patient's compliance history? What have been prior barriers to compliance? Is the patient able to comprehend and complete treatment requirements? Are there literacy, cultural, and/or language issues? Are there memory, visual, or hearing limitations? Is social support available to assist patients in understanding and implementing compliance strategies?

Malnutrition: Is the patient mild, moderately, or severely malnourished? Is the patient able to shop for groceries, cook, etc.? If not, is assistance available to provide meals? Is food affordable? Are dietary supplements indicated and affordable?

Functional Status

Self-care: Is the patient able to safely and adequately manage self-care activities such as bathing and dressing? Can the patient manage cleaning, cooking, laundry, and shopping? Is the patient able to make appointments, obtain and correctly take medications, manage a dietary regimen, and manage finances?

Ambulation and safety: Is the patient able to ambulate safely and access transportation resources? Do they use and/or need mobility aides (e.g., a cane, walker, or wheelchair)? Are they at risk for falling and/or household accidents? Do visual or hearing deficits put them at risk for injury?

Mental and Psychological Functioning

Mental status: Is the patient alert and oriented? Are memory and/or comprehension skills impaired? Is the patient able to follow through on recommendations, resource applications, etc.? Have any mental status changes coincided with new medication and/or increased doses?

Psychological status: Does the patient have a history or current symptoms of mental health problems (e.g., depression, anxiety disorder, drug/alcohol dependence, etc.)? Does the patient/family report symptoms associated with initiating dialysis or the ongoing demands of treatment? Has the patient been prescribed psychotropic medication and/or received counseling services? If so, has the patient found intervention helpful?

Legacy/End-of-Life Issues

Life reviews: Is the patient interested in and able to leave a written or recorded family history, life story, or words of wisdom to pass along to future generations? Are there regrets or alienation of family members the patient wishes to address and reconcile?

End-of-life care: What are the patient's wishes regarding end-of-life care? Does the patient have an advance directive? Has the patient discussed his/her wishes with family members? When does the burden of illness and care outweigh the benefit of continuing dialysis for this patient?

Withdrawal from dialysis: Has continued physical and/or mental deterioration raised the issue of withdrawing dialysis therapy? Has a catastrophic acute incident resulted in unlikely recovery? Are hospice services appropriate?

In addition to social work assessment through interviews, many excellent screening and assessment tools for physical and mental functioning, depression, and quality of life are available and are noted in DOPPS and the other research reviewed earlier. Once the assessment is completed, social work intervention is designed to meet identified goals.

MAXIMIZING SOCIAL FUNCTIONING

Living situation: If the patient is not living in a safe, affordable, and accessible housing situation, senior subsidized housing, handicapped equipped housing, or assisted living facilities may offer good alternatives. If a patient chooses to remain at home, removing hazards; installing grab bars, handrails, and ramps; and obtaining assistive devices may be indicated. Resources such as utility assistance, weatherization, and security measures may be needed.

Support system: Essentially all elderly patients (at least, at times) need the support of family and friends to deal with the treatment demands and functional capacity changes. Meeting with, educating, and soliciting participation of support members is key in securing their understanding and involvement. In addition to support system members, referrals to homemaker and personal aid services may be needed. Senior centers and adult day care facilities may be appropriate for socialization and supervision.

Social needs and meaningful activities: Often, due to loss of a spouse, declining health, and/or physical limitations, patients withdraw from enjoyable social activities. Assisting patients in identifying ways of overcoming barriers and reconnecting with friends, clubs, church activities, etc., is often important in enhancing a patient's quality of life. Activities in senior housing and senior centers are often positive outlets. Patients with limited vision may benefit from community resources for the visually impaired to access low-vision clinic services and support groups to cope with limitations. Identifying meaningful activities, hobbies, and interests and assisting patients in finding ways to pursue them is also important. Often community organizations, such as churches, have food pantries or mentoring programs in which seniors can volunteer.

Income: Many elderly patients have very limited incomes. Even with social security, work pensions, veterans' pensions, etc., in place, patients may not be able to manage basic needs. Referrals for federal, state, and local programs for food stamps, energy assistance, emergency financial assistance, etc., are often indicated.

Health care coverage: Many elderly patients may have and/or be eligible for Medicare, Medicaid, employer-related group plans for retired people, or private Medicare supplement plans. Close collaboration with facility business office personnel to assess adequacy of coverage is essential. Medicaid buy-ins for Medicare, kidney organizations, or state kidney programs may assist with Medicare and/or supplemental insurance premiums. For medication needs, Medicare D premium, deductible, and copay subsidies may be available. Helping patients understand, apply for, and utilize these programs is extremely important in helping them secure needed coverage and benefits. Health care coverage plans and medication programs are often confusing and in a state of flux, requiring constant monitoring and planning with patients and families.

Transportation: Planning appropriate and affordable dialysis transportation is often a challenge for elderly patients. Patients may no longer drive (and in some instances, should not be driving) and families may not be available to consistently assist. Utilization of public transportation vans, wheelchair vans, and/or Medicaid wheelchair transport is often indicated. Assisting patients and families in identifying emergency and/or backup transportation plans is essential, as is ongoing monitoring, as functional status and safety issues may change.

MAXIMIZING CARE AND COMPLIANCE

Comorbidities: As noted in DOPPS and the other research reviewed, elderly patients often have multiple comorbidities requiring monitoring and management. Planning for additional appointments, procedures, surgeries, and treatment regimens can be confusing and stressful. Clarifying and assisting elderly patients and their families in accessing various specialty services is extremely important. Coordinating needed services, such as diabetic education and follow-up and rehabilitation services, will facilitate needed care. In addition, social work coordination and advocacy with specialty services can help ensure that patients have access to the information and resources available through these specialty clinics. In the case of nursing home patients, close coordination with nursing home staff members is essential in addressing medical, nutritional, and psychosocial needs. Finally, nephrology social workers, aware of the implications of comorbidities on the functional capacity of the elderly, are in a position to provide needed support and assistance to patients and families in coping with the additional burdens and demands presented.

Although compliance of elderly patients with dialysis schedules has been found to be better than other age groups, other components, such as diet and medication, need to be monitored and addressed. Collaboration with staff in adapting teaching materials to meet patient needs (e.g., literacy/language skills, visual limitations, impaired hearing, comprehension and memory deficits, etc.) may enhance patient understanding and compliance. In addition, overcoming barriers, such as financial limitations, and soliciting the participation of the patient's support system contribute to improved compliance.

As noted in DOPPS findings, malnutrition is a significant issue for the elderly. While loss of appetite, among other factors, influences intake patterns, accessibility to food, interest in/ability to cook, and living alone without the social aspect of eating, may also contribute to decreased intake. Family assistance with cooking, homemaker services, Meals on Wheels and senior center meals offer access to nutritious meals. If dietary supplements are needed and not affordable, referrals to state programs, voluntary agencies, and/or provision of samples may be appropriate.

MAXIMIZING MENTAL AND PSYCHOLOGICAL FUNCTIONING

Impaired mental functioning (e.g., decreased memory and comprehension skills) is an important issue for some elderly patients and particularly for those living alone. If mental impairment exists and there is inadequate social support, patients may require assisted living or nursing home placement. While rare, elderly patients can face physical abuse or financial exploitation and, if suspected, this requires referral to state protective services.

Although the psychological well-being of elderly patients has been found in DOPPS and other research to be comparable to that of younger patients, it remains an area for intervention for some elderly patients, who are often coping with the loss of a spouse, adult children, and friends, as well as loss of independence and social isolation. Addressing increased anxiety, depressed mood, and/or other psychiatric problems for referral, medication, and/or counseling may be an important component of care.

MAXIMIZING FUNCTIONAL STATUS

As noted in previously reviewed research as well as DOPPS, it is well documented that the physical status and functional capacity of the elderly on dialysis are significantly less than younger patients. Physical and occupational therapy referrals may be indicated to increase independence in activities of daily living. Assistive devices for mobility, home safety measures, and home care assistance from family, friends, and/or community resources may be needed to maximize the functional status of elderly patients. Supervised exercise programs through dialysis facilities, the YMCA, or rehab programs to increase strength and flexibility may be essential in maintaining functional capacity. Finally, home equipment such as railings, bath bars, and elevated toilet seats may increase patient independence and safety.

MAXIMIZING LEGACY/END-OF-LIFE ISSUES

All elderly patients have a life story to tell. In addition to family history, either written or often oral, most elderly patients have survived an economic depression, multiple wars, some have experienced racism and segregation, and almost all have raised families, worked, and contributed to their communities. Encouraging and facilitating patients in recording their life story, either in writing or tape recording, can be a positive, life-affirming activity and an important history to leave their families.

Withdrawal from dialysis and end-of-life issues are addressed in another article in this issue, thus these issues are covered briefly here. Encouraging patients to consider an acceptable quality of life and under what circumstances they would wish to discontinue treatment are important issues to explore. Facilitating the completion of an advance directive and convening a family meeting to discuss the directive lays the groundwork for possible future circumstances and decision making. When the decision is made to discontinue dialysis, social work involvement, support to patients and families, and referral to hospice services are important components in easing the emotional impact of impending loss.

CONCLUSION

The elderly comprise a large and increasing percentage of the dialysis population. Among other challenges, they face increased comorbidities; decreased functional status, changes, and loss associated with aging; and increased mortality rates. Managing their medical, dialysis treatment, nutritional, and psychosocial needs and problems of elderly patients, in turn, challenge all members of the dialysis treatment team. The commitment and time devoted to addressing the special (and often changing) needs of elderly patients will determine not only the length of life, but perhaps more importantly, the quality of that life.

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CNSW ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION 2007 SPRING CLINICAL MEETINGS

AFRICAN AMERICANS' KNOWLEDGE AND BEHAVIOR REGARDING EARLY DETECTION OF KIDNEY DISEASE

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Kidney disease is an African American public health crisis. The first survey of African Americans about kidney disease was conducted by the National Kidney Disease Education Program (NKDEP), of the National Institutes of Health, to determine this population's knowledge and behaviors related to kidney disease. Using random-digit dialing, 2,039 African Americans were surveyed from seven states (GA, MD, OH, MS, LA, MO, TN). Even though almost half (43.7%) of the African Americans surveyed had a risk factor for kidney disease (including hypertension, diabetes, or a family history of kidney disease), only 2.8% reported that kidney disease was a top health concern for them. Less than half of surveyed respondents knew the correct definition of kidney disease (48.6%), knew a test to diagnose kidney disease (39.5%), and knew that African Americans were at higher risk for kidney disease (18.1%). Few understood the relationship between hypertension, diabetes, and kidney disease; less than 15% mentioned that kidney disease could be a negative consequence of unmanaged diabetes (13.6%), hypertension (12.1%), or a family history of kidney disease (2.4%). African Americans who were objectively at risk for kidney disease did not always perceive themselves to be at higher risk: 75% of African Americans with risk factors for kidney disease did not perceive themselves to be at higher risk. Only 37.4% of African Americans had ever been tested specifically for kidney disease. This study indicates that kidney disease is not currently perceived as an important health problem for African Americans, that they may not understand fundamental information about kidney disease, and that they are not taking action to prevent kidney disease. As the first national study of this topic, the conclusions are important in creating public health interventions to address this urgent problem and can help the nephrology team, including social workers, in targeting programs to most effectively reach this audience.

SOCIAL NETWORKS AND AFRICAN AMERICAN PATHWAYS TO KIDNEY TRANSPLANTATION

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The purpose of this study is to determine the relationship between African American dialysis patients' social network composition and their knowledge of kidney transplants. The hypothesis is that getting a kidney transplant is influenced by race and socioeconomic status through social network structure, which influences knowledge and attitudes about kidney transplant and leads to the behavior of getting a transplant workup. In preparation for this study, de-identified information about the race and insurance status of patients in each dialysis unit in the country was acquired from the U.S. Renal Data System 2004 Annual Data Report. Using this data, Chicago area hemodialysis units were selected with the highest case mix of race and income and several dialysis units were identified that have a majority of African American patients with income variation for the study. To confirm that there would be adequate variation in income, interest in kidney transplant, and status in the transplant pathway among African American Chicago-area hemodialysis patients, a pilot study with 32 patients was conducted in May 2006. The pilot study indicated that patients had varied incomes, and interest in kidney transplantation. The pilot study also suggested that African American dialysis patients in the Chicago area are still getting "stuck" on the pathway to kidney transplantation, and corroborates previous research. Almost half (48%) of the patients interested in a transplant never have been seen at a transplant center, and little more than half (55%) of the patients who have actually been seen at a transplant are still not on a kidney transplant list. Out all of the patients in the pilot survey who stated that they are interested in getting a kidney transplant, only 19% of them reported to be active on a kidney transplant list. This study will provide the first information available about African American ESRD patient social networks. This knowledge can be used to better understand racial disparity in kidney transplantation and provide insight that could be used for future social work research on this problem that may be able to decrease the rates of such disparity.

DEPRESSION, SOCIAL SUPPORT AND MEDICATION SELF-EFFICACY IN OLDER RENAL TRANSPLANT RECIPIENTS Karen Hamburger[1], Sarah Ryan[1], Cynthia L. Russell[2], Muammer Cetingok[3], Donna Hathaway[4], Rebecca P. Winsett[5]. Methodist University Hospital Transplant Institute, Memphis, TN, USA[1]; Sinclair School of Nursing, University of Missouri-Columbia, Columbia, MO[2], USA; College of Social Work, University of Tennessee, Knoxville, TN, USA[3]; College of Nursing, University of Tennessee Health Science Center, Memphis, TN, USA[4]; University of Southern Indiana[5].

As chronic renal disease increases in those aged 55 and over, renal transplantation also increases as a life-saving therapy that enhances quality of life, prolongs the lifespan, and reduces care costs. Depression, social support and medication self-efficacy can impact the outcomes of renal transplantation. Older renal transplant recipients are at risk for poor outcomes due to cognitive and physical changes associated with aging. This is the first study to describe the correlation between age and depression, social support and medication self-efficacy in the range of older renal transplant recipients. The study sample consisted of 50 renal transplant recipients aged 55 years or older in a mid-southern transplant center. Depression was measured with the Beck Depression Inventory. Social support was measured with the Social Support Appraisals Inventory. Self-Efficacy was measured with the Long-Term Medication Self-Efficacy Scale. Mean age was 60.5 years, 62% were females, 50% Caucasian, 30% with high school education, 56% disabled, and 83% received deceased donor kidneys. Six percent were prescribed CyA, 12% FK, 62% MMF/FK, 6% MMF, 6% MMF/CyA, 4% FK/AZA, and 4% MMF/sirolimus. Mean depression score was 2.2 (SD =2.3; range 0-9). Mean social support score was 34.49 (SD =11.14; range 23-78). Mean medication self-efficacy score was 103.58 (SD =10.18; range 100-135). Age was not correlated with depression (r =.187, p =.198) or social support (r =-.093, p =.527). Age was correlated with medication self-efficacy (r =-.442, p =.001). These findings indicate that older renal transplant recipients are not more depressed and they do not appear to have changes in social support. However, as renal transplant recipients get older, their self-efficacy in taking long-term medications is decreased.

QUALITY OF LIFE RESPONSES FROM LIVING RELATED, EMOTIONALLY RELATED AND PUBLICLY SOLICITED LIVE KIDNEY DONORS OF DIVERSE ETHNICITIES. Patricia McDonough and Mary McKinney Montefiore Medical Center Bronx, NY

Purpose: Published transplant quality of life literature generally concentrates on white traditional donors. This study evaluated the satisfaction of minority and publicly solicited living kidney donors.

Method: A questionnaire in English and Spanish was sent to 268 traditional live donors (TLD) who donated between January 1, 1999 and December 31, 2003. It was sent separately to 26 live donors who volunteered because of public solicitation (PSD) from 2001 to 2006. Sample questions: "During your evaluation, did you receive adequate information?" "How did your family members react to your donation?"

Results: 75/268 (28%) TLD questionnaires were returned. Responses from Hispanics(H) 39%, African Americans (AA)17%. 23/ 26 (88%) questionnaires sent to PSD were returned. Responders and non-responders had similar demographics. Responders: H: 48% male, age 19-65 years. AA: 50% male, age 18-59 years. PSD: 65% male, age 23-59 years. Education: primary school through college (higher college education in PSD group). Responses were positive; suggestions for improvement included more follow-up after donation, more information on long-term effects of donation and more education in minority communities regarding donation.

Conclusions: Minority and solicited live kidney donors are informed and feel positive about donations.

RELAXATION THERAPY IN THE NEPHROLOGY SETTING: IMPLICATIONS FOR PRACTICE

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This study examined the effectiveness of relaxation techniques with patients of a regional hospital-based Nephrology Program using a qualitative methodology. The initial sample consisted of twenty-five participants of all treatment modalities. Respondents were asked to complete a survey. All participants finished one to five relaxation therapy sessions over a 6-month duration. Relaxation techniques consisted of progressive muscle relaxation, deep breathing, guided imagery and refocusing. One year later a random sample of twenty-one participants were surveyed to measure if relaxation skills (a) were continuing to be utilized, (b) continued to be effective, (c) were useful to justify recommendation.

Results suggest that the patients were overwhelmingly pleased with relaxation as an effective technique to assist with amelioration of caregiver stress, anxiety, sleep disturbance, fear of needles, difficulty coping, fear of dialysis and pain control. One year later, 90.5% of respondents are continuing to practice the relaxation skills taught to them. 100% of the respondents indicated that they would recommend this therapy to others. Implications for practice might include Relaxation Therapy as a complementary tool to assist patients during invasive surgical interventions.

A SIMPLE FEEDBACK TOOL TO ENHANCE PATIENT EDUCATION ON ADVANCE DIRECTIVES

Marcia Sawyer, Botsford Kidney Center, Livonia, MI, U.S.

Using a short self report form to solicit patient feedback after providing education and counseling on Advance Directives has doubled our measurable results and has served as an icebreaker for discussion on this sensitive topic.

Previous attempts to increase our dialysis patients' understanding of Advance Directives through social work education and counseling did increase the number of patients with written Advance Directives from approximately 4% to 18% of our patient population. In addition to individual teaching and counseling, we provided patients with fact sheets and brochures, placed Advance Directives information in the patient areas, put up question and answer bulletin boards, and held patient support group discussions on end of life issues. In 2006, we continued to use these methods, but with one addition. After social workers counseled patients about Advance Directives, they asked the patients to fill out a short (1/3 page) written checklist. The purpose of the checklist was to solicit the patients' responses to the information presented and to allow the patients to state their wishes about Advance Directives. Patients were given these choices: (1) I have an Advance Directive on file that expresses my current wishes, (2) I have one at home, (3) I want further information, (4) I am considering writing an Advance Directive, or (5) I am not interested in having an Advance Directive at this time. Space was included for comments.

Since we have asked patients to give a brief, but formal response to the education we provide, we have seen an increase in the number with written Advance Directives to over 30% of our population. Patients who filled out checklists were more likely to seek information on Advance Directives, engage in discussions of end of life planning, and to complete or to update an existing Advance Directive.

This simple tool requires patients to take an active role in education, and provides the facility with a concrete documentation on patient education without the staff having to do more paperwork.

PROMOTING SELF-CARE IN HEMODIALYSIS

Tracey Tyus-Bailey, Kristie Lewis
Greenfield Health Systems, Bingham Farms, MI, USA

Positive adjustment to hemodialysis is a key determinant in the quality of life and longevity for individuals with CKD (Chronic Kidney Disease). Social workers assist with the adjustment to illness and improved quality of life by providing education, supportive counseling, advocacy, and facilitating patient to staff, and patient to patient interactions. Promoting self-care in addition to these services empowers patients to gain control and independence.

In collaboration with the multidisciplinary team, social workers surveyed patients in the unit to assess their interest and willingness to engage in a self-care program. All interested candidates received literature regarding the latest education and information for self-care, cannulation, and the importance of vascular access, a glossary of treatment terms and medications, and various dialysis machine specifics. Self-care began with patients obtaining their own temperatures and weights, cleaning their access site, with progression to self-cannulation; under the supervision of clinical staff.

This process was expected to preserve their access, increase patients' sense of control and decrease rates of hospitalization.

Creating a self-care program utilizing social workers as program developers and change agents proved effective at Greenfield Health Systems-Detroit Northwest Dialysis and Lahser Units. Social work interventions with staff and patients were successful as evidenced by an increased number of patients practicing self-care techniques and a significant number of those self-cannulating. This was achieved through positive rapports, education, peer mentoring, and individual coaching with motivational techniques.

In conclusion, the social worker's formal education and training to assess, counsel, empower, educate and advocate proved foundational to increasing patient satisfaction and participation in their medical regimen while improving quality of life.

National Kidney Foundation
CNSW
THE COUNCIL OF NEPHROLOGY SOCIAL WORKERS

CNSW RESEARCH GRANTS PROGRAM

Purpose

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

Areas of Interest

1.) Research on psychosocial factors in CKD

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

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

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

Eligibility

Grant applicants must meet the following eligibility requirements:

A. Membership in CNSW

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

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

D. Residence in the United States or its territories

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

Grant Requirements

Each grant recipient is responsible for:

- Conducting the project as set forth in the proposal
- Obtaining IRB approval and maintaining data in a confidential manner
- Completing the project within the specified time frame
- Providing financial reports as required by the National Kidney Foundation
- Acknowledging NKF-CNSW grant assistance on all publications arising out of the grant
- Submitting progress reports and a final report within 60 days of the end of the grant year
- Presenting a paper at the NKF Spring Clinical Meetings
- Submitting a manuscript based on the results to *The Journal of Nephrology Social Work*

Funding

CNSW annually requests grant monies from NKF. One or more grants will be awarded from the $20,000 budgeted in the next fiscal year. Grant applicants submitting to more than one granting agency will be awarded the difference between the amount awarded by the other agency and the amount applied for from CNSW. CNSW grants assist in defraying the cost of research and projects. They are not intended to cover the entire cost of the research.

Funds may not be used for the purchase of equipment. Budgets must allocate $750 for airfare and one night's accommodation to enable grantees to present their research at the NKF Spring Clinical Meetings. Funding for CNSW research grants runs from July 1 of the year of approval through June 30 of the following year.

How to Apply

If you are interested in preparing a proposal, please submit a letter of intent to the CNSW Research Grants Program, National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016 by October 15, 2007. The letter of intent must include the following:

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

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

Review Schedule

October 15	Letter of intent due
November 30	Proposals due
January/February	Review by CNSW Grants Coordinator and CNSW Research Grants Committee
March 14	Awards announced
July 1	Approved projects begin operation

Further Information

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