The Journal of
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Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of nearly 1,000 social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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

- Social Work Outcomes
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- End-of-Life Concerns
- Sleep Disorders
- Sexual Functioning
- Aging and Gerontological Issues
- Disaster Preparedness
- Comorbid Illnesses
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INSTRUCTIONS FOR AUTHORS

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

The *JNSW* is a peer-reviewed publication. Manuscripts are accepted for review with the understanding that the material has not been previously published, except in abstract form, and is not concurrently under review for publication elsewhere. Authors submitting a manuscript do so with the understanding that, if it is accepted for publication, the copyright for the article, including the right to reproduce the article in all forms and media, shall be assigned exclusively to the National Kidney Foundation. The publisher will not refuse any reasonable request by the author for permission to reproduce any of his or her contributions to the *Journal*.

Exclusive Publication**:** Articles are accepted for publication on the condition that they are contributed solely to *The Journal of Nephrology Social Work*. Authors should secure all necessary clearances and approvals prior to submission. All manuscripts are peer-reviewed by two reviewers. Receipt of manuscripts will be acknowledged within two weeks, and every effort will be made to advise contributors of the status of their submissions within eight weeks.

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 to the manuscript.

TYPES OF ARTICLES BEING SOUGHT

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

Reports and Commentary. The *JNSW* welcomes articles that describe innovative and evaluated renal social work education programs, that report on viewpoints pertaining to current issues and controversies in the field, or that provide historical perspectives on renal social work. Commentaries are published with the following disclaimer: "The statements, comments or opinions expressed in this article are those of the author, who is solely responsible for them, and do not necessarily represent the views of the Council of Nephrology Social Workers or the National Kidney Foundation."

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, method, results, and discussion of original research. Length usually should not exceed 15 double-spaced pages, including references.

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

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

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

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

MANUSCRIPT SUBMISSION

IMPORTANT UPDATE: *JNSW* now has an optional MS Word template available for typing in your article. Using it will speed along the production process and allow you to see what your article will look like when it is typeset—as it is being written. To have this template emailed to you, send an email with "Template Needed" in the subject line to **jnsw@kidney.org.**

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

Manuscript Format.

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

Manuscripts should conform to the following guidelines: Text should be double-spaced, set in 12-point type (preferably Times New Roman) and have 1-inch margins along all sides of every page. Starting with the title page, pages should be numbered in the upper, right-hand corner and should have a running head in the upper left-hand corner. The running head should be a shortened version of the manuscript's title and should be set in all uppercase letters. The first line of every paragraph in the manuscript should be indented, as should the first line of every footnote.

Order of the Manuscript Sections

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

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

Abstract. The manuscript's abstract should be set on its own page, with the word "Abstract" centered at the top of the page. The abstract itself should be a single paragraph with no indentation and should not exceed 120 words. All numbers—except for those that begin a sentence—should be typed as numerals. Running heads and page numbers should continue from the title page.

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

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

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

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

Footnotes. A footnote should be indicated in the text of the manuscript with a superscript Arabic numeral to the right of the pertinent material. The footnotes should be listed on a separate page with the word "Footnotes" centered at the top of the page. They should be listed sequentially, with the first line of each note indented. Running heads and page numbers should continue from the author note. Do not use software functions that automatically format your footnotes. This can cause the footnotes to be lost when the manuscript is formatted for typesetting.

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

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

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

Figure 1. Exemplary formatting for all figure captions.

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

Note: All tables, figures, and graphs must be produced in black and white (grayscale), high resolution format.

Reference Examples

Journal Article, Two Authors

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

Journal Article, Three to Six Authors

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

Journal Article, More Than Six Authors

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

Journal Article in Press

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

Complete Book, Edited

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

Chapter of an Edited Book

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

Article from a Journal Supplement

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

Abstract

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

Editorial

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

REVIEW PROCESS

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

AFTER ACCEPTANCE

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

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

Julie Régimbald, MSW, RSW, Cindy Gill, MSW, RSW, The Ottawa Hospital—Riverside Campus, Ottawa, Ontario, Canada

This review of 35 research and anecdotal reports discussing psychosocial barriers to home dialysis explores the challenges and successes of home dialysis from the viewpoints of both patients and nephrology professionals. The literature identified multiple psychosocial barriers to successful home dialysis: physical ability, cognition, patient attitudes toward home dialysis, emotional impact on the patient, emotional impact on the family, support from family, whether patient or caregiver is responsible for treatment, time constraints, patient personality and mental health, safety and patient's adherence with procedures, suitability of patient's home and willingness to change it, cultural issues, language barriers, unplanned start on dialysis, policy differences between modalities, loss of relationships with staff and other patients, support from staff for home dialysis, knowledge barriers, cost to hospital/staff availability to train and maintain home dialysis patients, and cost to the patient. Assessment tools already exist. The Jo-Pre-training Assessment Tool (JPAT) is a screening instrument which assesses the suitability of candidates for home dialysis, either peritoneal dialysis (PD) or home hemodialysis (HHD). It is designed to identify health-related problems; candidates are then referred to the appropriate professionals among the multidisciplinary team for assessment and care before starting training. The Method to Assess Treatment Choices for Home Dialysis (MATCH-D) was also developed to assess patients' suitability for home dialysis (PD or HHD), screening for medical and social barriers. However, we were not able to find a comprehensive tool specific to psychosocial barriers experienced by patients and their families. Based on the literature review, we concluded that psychosocial aspects are significant factors influencing the patients' ability to maintain home dialysis. To this end, the authors are developing a new tool: the Psychosocial Assessment Tool for Home Dialysis (PATH-D).

INTRODUCTION

We limited our search to articles discussing psychosocial barriers to home treatment modalities. Home hemodialysis (HHD) has been in use since the 1960s, and peritoneal dialysis (PD) since the mid-70s, and are used extensively around the world with varying rates of success. In Australia and New Zealand, data from 2008 revealed that between 30% and 40% of dialysis patients performed their treatments at home (Agar, 2008); in the UK, 25% of dialysis patients were on PD (Lindley, 2006) while HHD was not being widely offered; and in Finland, the rate of home dialysis was 24% in 2007 (Honkanen & Rauta, 2008). Comparatively, the United States, had a home dialysis rate of less that 8% (Jennette, Derebail, Baldwin, & Cameron, 2009; Schatell, 2007), and in Canada the rate of home dialysis in 2008 was 12.9% (Canadian Institute for Health Information (CIHI), 2010).

In Ontario, Canada, The Provincial PD Joint Initiative Committee in 2006 had set a goal of increasing the rate of PD from 14.7% in 2008 to 30% by 2010 (CIHI, 2010). Data supports that there are physiological benefits to home dialysis, such as improved patient survival and a reduction in cardiovascular risk, as well as advantages pertaining to quality of life, and social and economic aspects (Masterson, 2008). Masterson (2008) indicates that these benefits outweigh the disadvantages associated with the application and time commitment required for training, the potential for relationship strain, and reluctance to "hospitalize" the home (p. S16).

Medical contraindications for PD include abdominal adhesions from past surgeries, severe peripheral neuropathy which involves progressive deterioration of nerve endings, and in some cases, severe polycystic kidney disease (Brey & Jarvis, 1983). Other than medical appropriateness, Schatell (2007) suggests that many patients may succeed with PD or HHD, such as those who drive a car and use many abilities similar to the ones required to perform these treatments: "hand-eye coordination, doing steps in sequence, feeling overwhelmed at first and then adjusting to the routine, and the life-and-death nature of the task" (p. 44). Agar (2008) reports that such "simplistic approaches" (p. S27) as answering positively to "do you drive?" may be helpful, but adds that some non-drivers who use comparable skills, for instance people who operate a sewing machine, would also be suitable. These approaches ignore the complex psychological and social impact on individuals and families assuming responsibility for rigorous medical procedures. While they could be used for initial screening, further assessment is required.

Medical treatment does not happen in a neutral setting. While there is a tendency to focus on medical outcomes in determining the "best" treatment modality, a patient-centered assessment will also explore potential outcomes related to work, family, and social life. Raphael (2009) states that the social determinants of health ("…the economic and social conditions that influence the heath of individuals...") are reliable indicators of successful health outcomes. As such, it is incumbent upon us to acknowledge the nonmedical factors influencing a patient's ability to succeed on home dialysis, and to attempt to improve the patient's situation.

BARRIERS

Barriers Linked to Physical Ability

Assessments of the patient's physical ability should take into account manual dexterity as well as the need to lift, move, and dispose of the dialysis supplies. Hodge (2008) acknowledges the importance of considering the physical abilities of HHD candidates. Brown (2008) states, "The problem is to determine if frail elderly, who often have considerable comorbidity such as impaired vision or hearing, poor mobility, arthritis and cognitive problems, can cope with the rigors of a home treatment.

"Data from Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD) [http://www.necosad.nl/xcms/text/id/279] show that the main reasons for not choosing PD were age, being female, and living alone. Patients 70 years or older were six times more likely to choose in-center HD than those aged 18–40 years…" (Brown, 2008, p. S70).

If a patient does not have the physical ability to manage either PD or HHD themselves, then a support system is needed to enable home dialysis. For those who have a good support system, family members in particular are often willing to help with all or part of the procedure. The increased use of community nurses enables frail patients to be on PD in their own homes (Brown, 2008, S69). In Canada, some provinces provide funding for home care nurses to assist PD patients as a way of promoting PD. We recognize that government-funded home care support may not be available in other countries.

Cognitive Barriers

Loos-Ayav, Frimat, Kessler, Chanliau, Durand, and Briançon (2008) find that one of the main factors limiting patient education is impaired cognitive function. Home dialysis requires the ability to learn and consistently perform a complex task, along with the ability to problem solve. Hemodialysis is generally acknowledged to be more demanding than PD. Hodge (2008) acknowledges the need to consider the mental status and skills of the patient when HHD is offered, and estimates that 50% of patients could successfully perform hemodialysis at home (p. 1). Robert Lockridge, MD, maintains that "active drug and alcohol abuse, and severe mental retardation" are the only exclusion criteria for HHD (Munasque, 2010). This may be the case in home dialysis programs which require the availability of a trained helper, but for patients who self-administer their dialysis treatments, a thorough assessment of the patient's cognitive abilities is necessary.

When memory problems are evident, the patient does not necessarily have to be excluded from home dialysis. The training nurses can adapt the teaching process by providing extra help and repeating procedures many times (Palmer, 1978).

Teaching patients presents its own challenges, as the mental and physical manifestations of illness affect the ability to learn during training (Wong, Migram, Halifax, Eakin, Cafazzo, & Chan, 2009). "Learning problems and emotional resistance may impede…[the] educational process" and the social worker can become a resource person for the nurses and technicians who are training the patients, indicates Palmer (1978, p. 365).

Attitudinal Barriers

McLaughlin, Manns, Mortis, Hons, and Taub (2003) examine the reasons why patients do not select self-care dialysis. Their definition of self-care dialysis includes HHD, PD, and self-care in-center hemodialysis. They identify knowledge barriers (lack of a satisfactory explanation of the various techniques); attitudinal barriers (belief that patients should not dialyze without direct supervision; fear of failure to perform self-care dialysis adequately; and fear of social isolation); and skill barriers (needle phobia and lack of space at home). They note that attitudinal barriers are generally considered the most difficult to overcome.

Cafazzo, Leonard, Easty, Rossos, and Chan (2009) studied patient-perceived barriers to nocturnal home hemodialysis (NHHD). The major barriers identified by chronic hemodialysis patients were lack of self-efficacy (estimation of one's capacity to engage in behaviors that contribute to desired health outcomes in performing the therapy (p. 787)), lack of confidence in self-cannulation, and length of time on current therapy. From the qualitative analysis, similar themes were found: burden on family members and fear of a catastrophic event without nurses' support, which patients perceived as loss of safety (pp. 786–787). The patients' belief that hemodialysis was too demanding or too dangerous to be performed outside a medical center was a significant obstacle. The authors found that, despite significant potential improvements in overall health, cardiovascular health, and sleep quality, as well as elimination of dietary restrictions, the adoption of NHHD was limited (p. 784). PD patients found the regimen demanding and difficult to balance with other daily activities, yet some felt empowered through greater involvement in their health care (Lehoux, 2004).

Van Eps, Jeffries, Johnson, Campbell, Isbel, Mudge, and Hawley's 2010 study on quality of life and alternating treatments of NHHD enumerates the benefits of frequent HHD; yet, patient preference and motivation are intrinsically linked to psychosocial supports. Increasing patient motivation was found to be the key to success in self-care by nephrology professionals. Creating a thorough understanding of the pros and cons of different therapy alternatives should be the foundation for increasing motivation, although the physicians felt that simplification of the dialysis procedure was more important (Ledebo, 2008).

Patients who experience secondary gains from their dependence on staff and family members, or their role as "the chronically ill person" may be reluctant to switch to home therapy offering the possibility of increased independence (Brey & Jarvis, 1983).

Emotional Impact on the Patient

Jennette, Derebail, Baldwin, and Cameron (2009) find that patient choice of treatment modality is heavily influenced by the perceived impact on lifestyle and schedule. Palmer (1978) mentions that anxiety in home dialysis is aggravated by the fact that the patient and partner are expected to administer their own "traumatic and complicated" treatment away from a medical center (p. 368). She adds that for patients who are depressed from the repercussions of dialysis on their lifestyle and/or their self-image (loss of body function and increased dependency on others), treatment should begin before patients are entrenched in the "sick" role and overwhelmed by the pessimism that feeds their depression (p. 371).

Wong, Migram, Halifax, Eakin, Cafazzo, and Chan (2009) indicate that educators need to be attentive to self-treatment being a socially situated activity. They anticipate that the primary factor determining whether or not the patient could take on the responsibility of self-care would be the challenge of managing complex medical technology. However, they conclude that psychosocial dimensions of home dialysis (e.g., family responsibilities, coping skills, life style) also determine whether home dialysis is viable. Loos-Ayav et al. (2008) also find that a certain psychological competence is required in order to perform self-care dialysis (PD or HHD unassisted by a nurse).

Patients' adjustment to the impact of dialysis on their social and recreational activities will have a significant influence on their compliance with medical procedures (Peterson, 1984, p. 34). Peterson (1984) explains that dialysis patients may experience fatigue due to anemia, stress related to eating and drinking, and sexual difficulties such as impotence.

"The nephrology social worker is the only member of the treatment team whose professional orientation is geared towards the psychosocial management of chronic renal failure" (Peterson, 1984, p. 42). Therefore, the social worker's role should include the facilitation of communication between disciplines, and between the patient and the team. Peterson also adds the need for social workers to teach the staff about "the importance of the interaction between their responses to the patients, the medical management of the illness, and the patient's long-term psychosocial adjustment" (Peterson, 1984, p. 43).

For HHD, responsibility for operating the dialysis machine and fear of self-needling can seem overwhelming for some patients (Cafazzo et al., 2009; Masterson, 2008; Wong et al., 2009), both of which can cause anxiety and problems with sleep (Masterson, 2008). Fear of self-needling was also identified as a common barrier by Bessie Young, MD, MPH (Munasque, 2010). Cafazzo et al. (2009) report that the loss of nursing support in critical situations was perceived by patients as a loss of safety (p. 787), and patients feared a catastrophic event.

Emotional barriers to PD include: fear of infection, peer experiences with peritonitis, fear of isolation, and lack of supervision, as well as having small children in the home (Jennette et al., 2009). Wong et al. (2009) mention anxiety related to uncertainty over the training period and the shift of medical responsibility from practitioner to patient. According to Hodge (2008), the convenience of not having to travel to the dialysis unit, and having a flexible schedule when performing hemodialysis at home is often outweighed by different fears (self-needling, technology, impact on a relationship with a caregiver, inability to function while ill, inability to handle emergencies, and giving up a dependency relationship with staff from the center or social support from other patients). The author believes that the physician should prescribe the modality that will provide the best probability of longer and better quality of life, and give the patient the facts about the differences in outcomes between the different modalities, with nocturnal hemodialysis providing the best outcomes. Hodge suggests that fears can be overcome if the patients participate in a short in-center frequent dialysis trial as they will experience the benefits of more frequent dialysis.

Courts and Boyette (1998) conducted a comparative descriptive study exploring the anxiety, depression, and psychosocial adjustment of male patients on three types of dialysis—HHD, in-center hemodialysis, and PD, with 5 patients from each modality. They state that chronic illnesses challenge the coping mechanisms of patients and their families and demand behavioral and emotional changes. Patients on dialysis have unique problems because they may not appear to be ill, therefore, they often feel pressured to live normally. Other problems include lifestyle changes required to perform dialysis, inability to work due to dialysis time constraints, as well as loss of status, social position, family roles, and independence. By using the Clinical Anxiety Scale (Corcoran & Fischer, 1987), the Generalized Contentment Scale (Hudson & Proctor, 1977), the Hemodialysis Stressor Scale (Baldree, Murphy, & Powers, 1982), and the Psychosocial Adjustment to Illness Scale—Self-Report (Derogatis & Lopes, 1983), Courts and Boyette (1998) observe that the patients on HHD had the highest level of psychosocial adjustment to illness, the lowest anxiety scores, and the lowest depression scores. The PD patients had the highest anxiety scores, while the highest depression scores were for the in-center HD group. These authors conclude that HHD patients fare much better than their counterparts, largely due to their ability to control scheduling and length of treatments, an increased sense of overall control, and the ability to use dialysis time for a variety of activities in the home. PD patients share similar experiences with those on HHD, and might be expected to experience high psychosocial adjustment to illness. The difference in this study may be that the HHD patients had dialysis partners, while the PD patients generally performed their own treatments.

Altered body image is identified as one factor which influences patient acceptance of the treatment (Lehoux, 2004). Lehoux`s research underlines the importance of the individual patient's values (e.g., ability to accept the merging of their physical body with medical technology; valuing independence and autonomy) and self-image (e.g., image of self as capable of technical competency, body image) in determining who will successfully integrate home therapy into their life.

Results of a study by Buss (2008) show improved quality of life (QOL) in HHD patients, particularly in the role-physical (limitations in usual role activities because of physical health problems), vitality (energy and fatigue) and social functioning (limitations in social activities because of physical and emotional problems) domains of the Medical Outcomes Survey Short Form (SF)-36. This study also revealed that "an overall sense of well-being is indicated with benefits of increased energy, strength, and endurance, which is a most desirable outcome from a social work perspective" (p. 14). This is of importance to social workers, who advocate for the best QOL possible for patients. Buss adds that the patients who were trained for HHD but returned to other modalities had found the experience overwhelming (30% dialyzed without a partner), had complicated medical issues, or had an assistant who had difficulty (13% of them dialyzed with their partner doing all of the procedures) (p. 14). From that article, HHD patients consistently reported feeling much better after entering the HHD program, and most valued the freedom in scheduling their own dialysis, and the opportunity to be involved in other activities, such as continuing to work, volunteering, and being more involved with their families (p. 15).

Impact on the Family

Cafazzo et al.'s 2009 study found that, in multiple instances, family members who were primary caregivers recognized their lack of appreciation of the extent of patients' conditions until therapy was administered at home. The authors conclude that family members might be fearful of complex home therapy, and that there would be additional patient care responsibilities (p. 786). For some patients, needing a helper made HHD unappealing (Jennette et al., 2009).

Partner or helper burnout was identified as a potential issue by Bessie Young, MD, MPH (Munasque, 2010). Masterson (2008) indicates that there is potential for relationship strain or "burnout," especially when the person providing the assistance with dialysis has employment that requires traveling or shift work. When partners are assuming the major responsibility of the treatment, the social worker, who is trained in problem solving, can help the team deal with difficult family dynamics, as well as assist the family and patient in accepting the new situation and the feelings of dependency brought on by the continued necessity of treatment (Palmer, 1978).

Polaschek (2005) reports patients acknowledging that, in general, their family, especially their wives, now provide increased support for them and this comes at a cost to these family members, not only through limiting their own activities to the house during treatment, but also increased stress from sharing responsibility for treatment.

"Several small studies and anecdotal reports have found that the added responsibility of home hemodialysis can generate fear, hostility, anxiety, and fatigue in caregivers, and negatively affects family and other social relationships" (Van Eps et al., 2010, p. 36). In a letter from Bernheim and Korzets (1999), the authors report that helpers and/or other family members of patients on HHD were often affected psychologically, namely with insomnia and nightmares often related to the dialysis procedure, as well as extreme anxiety affecting their functional ability. Van Eps et al. (2010) also note, in their study as well as others, that the majority of successful caregivers for HHD patients are female and that fewer female dialysis patients enjoy the benefits of home-based dialysis therapy as a result of lack of family support. "Increasing numbers of women are now juggling paid employment in addition to household chores and family responsibilities. This leaves them little time for meeting their own health and leisure needs. These observations have important implications for patient recruitment [to home hemodialysis], as well as social support provided by home hemodialysis units' staff to patients and their families" (p. 37). Improving our understanding of the impact of family dynamics on home dialysis may also assist in expanding the patient population that can be successfully maintained with home therapies (p. 37).

A literature review conducted by Brunier and McKeever (1993) clearly revealed that the majority of family members assisting or carrying out HHD were female. They conclude that the majority of women work outside the home and that, "as heads of household[s], home dialysis may place an even bigger physical and emotional burden on female caregivers" (p. 658).

Support from Family

Van Eps et al. (2010) emphasize the importance of a good social support network, as it has been shown to improve compliance and outcomes in hemodialysis patients and is often critical for the success of home-based dialysis therapies, although "home-base[d] dialysis may place an extra load of responsibility upon family and friends" (p. 35).

For Hodge (2008), not having a helper constitutes one of the three exclusion criteria for HHD. The Method to Assess Treatment Choices for Home Dialysis (MATCH-D) (Schatell & Witten, 2009) also screens out potential HHD candidates who do not have a helper at home. Lack of support for home care from families was one of the two most common barriers to self-care identified by the volunteers from the European Dialysis and Transplant Nursing

Association/European Renal Care Association (EDTNA/ERCA), the other being language barriers (Lindley, 2006). At the authors' Ottawa Hospital, patients can perform HHD on their own, provided they are linked with a personal alarm system.

Patient versus Caregiver Responsibility for Performing Dialysis

Agar (2008) indicates that caregiver fatigue is often identified as the cause for stopping HHD, especially in North America, whereas in Australia and New Zealand, there is an effort to ensure that the responsibility for care falls on the patient. In one study, it was found that dialysis partners often felt too great a responsibility, and this led to stress situations (Lindley, 2006). In Lehoux's 2004 study, a patient's wife "found the manual PD a burden—four times a day… it's like being in jail, you can't go anywhere" (p. 6). Agar (2008) reports that when patients take responsibility for their own care, the caregivers experience less emotional and psychological stress. The caregivers can then take a support role regarding dialysis instead of being the facilitators. In addition, Lindley (2006) notes that when patients attend training knowing that they cannot rely on anyone else, they seem to concentrate better, increasing their chances of becoming more self-sufficient.

There is recognition that even when partners need to take some responsibility for a home treatment modality, the burden might be less than some of the responsibilities associated with in-center dialysis, i.e., arranging and paying for transportation three times per week for in-center hemodialysis, and preparing meals that take into account a more restrictive diet and a more vigilant monitoring of fluid intake (Schatell, 2007).

In some countries, automated PD is used as the preferred modality when patients need assistance, with two visits from the nurse to connect and disconnect from the machine. PD patients from the Ottawa Hospital can receive this type of home support, which makes home dialysis a viable option for many elderly patients. The patient or caregiver only needs to be able to respond to alarms from the cycler, and/or contact the nurse on call who can guide them.

Courts (2000, May) conducted a study investigating the psychosocial reactions of patients on HHD and their dialysis partners, how decisions were made to choose HHD, and the patients' perceptions of HHD stressors. She studied 14 patients and their partners. Of the sample group, only 2 patients actually participated in the dialysis process; the other 12 patients had a caregiver perform their dialysis. Results showed that patients enjoyed not needing to depend on dialysis technicians and appreciated the freedom to dialyze at their convenience, which increased their sense of control over their lives. The dialysis partners found HHD stressful, although this stress decreased over time. Anxiety and depression scores were low for both patients and their partners, compared to other dialysis patients. Courts emphasizes the need to assess patients and their partners carefully, and recommends time with each to talk separately about their concerns and wishes. She also recommends providing relief for the dialysis partner. At the Ottawa Hospital, HHD patients can receive "respite" in the form of a few treatments in-center when they or their partners need time off from the responsibilities associated with performing hemodialysis at home. Patients on HHD must switch to in-center HD permanently when they can no longer manage their treatment at home and no family assistance is possible, as there is no community assistance coverage for HHD.

Loos-Ayav et al. (2008) found that after one year of being on HHD, autonomous patients had better health-related quality of life scores than in-center dialysis patients for the dimensions "burden of kidney disease, role-emotional, cognitive function and effects of kidney disease" (p. 6). The authors attribute higher quality of life scores to lesser dependence on others and a more positive outlook regarding the effects of kidney disease on their daily activities. They also found that the autonomous patients were more active than the in-center patients, more frequently having an occupation or doing leisure activities. They conclude that even though some patients had limited autonomy due to age, comorbid factors or disabilities, their participation in self-care hemodialysis is to be encouraged.

Cafazzo et al.'s (2009) qualitative research reveals that patient concerns about the burden on family members were a barrier to choosing NHHD. Munasque (2010) confirms this: "The partner needs to be treated like a living donor. They need a full explanation of what they're committing themselves to. They need a chance to say 'no' in private."

The social worker can help with communication between the patient and the dialysis partner. It is important to assist the patient and the dialysis partner in understanding their roles and responsibilities, and to problem solve communication issues. For example, Palmer (1978) reports that frustrations and resentment can arise when the patient dominates the partner and has little appreciation for their efforts, or when the dialysis partner takes too much responsibility for the patient's treatment.

Time Required

Training time for HHD was found to be a barrier by Agar (2008). Lindley (2006) also finds that the training period for HHD (8 to 10 weeks, compared to 4 to 5 days for PD) was a major drawback. Masterson (2008) also reports this as being an issue, even though the study sample's training time for HHD was 3 to 6 weeks, and was considered especially difficult for people working full-time or for those living in rural areas who had to relocate temporarily during training.

Time constraints are also identified by Jennette et al. (2009) as a reason why PD is less desirable. All of Lehoux's (2004) subjects experienced major obstacles with employment because of the frequency and/or duration of treatment.

Female patients often do not consider HHD because of their other responsibilities within the family (Lindley, 2006; Palmer, 1978). In Spain, the number of HHD patients declined, in part due to the difficulty of recruiting female patients (Lindley, 2006).

Patient Personality and Mental Health

Of the articles reviewed, only a few, such as Kaplan, De-Nour, and Czaczkes (1976), mention that personality traits and psychological condition can be contraindications to home therapies. Depression is mentioned frequently (Courts 2000; Courts & Boyette 1998; Kaplan, De-Nour & Czaczkes, 1976; Palmer, 1978; Schatell 2007) as a by-product of ESRD, so while it is clear that a degree of depression might be a contraindication to home dialysis, it is not clear what weight is placed on the patient's overall mental health.

Kaplan, De-Nour and Czaczkes (1976) identify personality traits and mental health issues that can be assessed prior to starting dialysis, such as frustration tolerance, obsessive-compulsive tendencies, acting out aggressively, depression or suicidal ideation, denial of sick role or excessive gains from the sick role, rejection of dependency needs, and satisfaction with work as potentially predicting the person's behavior during treatment. These authors mention that clinicians have a "tendency to over-rate patients' potential for adjustments, i.e., to under-rate the stressfulness of the situation" (p. 330). Personality traits such as irresponsible behavior from the patient or assistant (e.g., excessive alcohol consumption) can interfere with home dialysis due to the responsibility involved (Palmer, 1978), although patients who are depressed, angry, or disruptive in-center may actually do better at home (Schatell, 2007).

It seems evident that patients who cannot reliably act in their own best interests would be at greater risk for harm if given responsibility for their own dialysis.

Safety and Patient Ability/ Willingness to Follow Recommended Procedures

Giles (2003) discusses observing unsafe working/living conditions, such as HHD patients storing blood in the kitchen refrigerator. The author states that this highlights the need for the development of health and safety protocols for dialysis within the home environment.

In Australia and New Zealand (ANZ), home visits are made by nursing and/or medical staff, and technicians do machine maintenance in the home on a regular basis, but contrary to "service calls," some patients don't want intrusions in their home (Agar, 2008). At the Ottawa Hospital, the patients on PD are visited at home by nurses, and the HHD patients are also visited by technicians.

Wong et al. (2009) emphasize the need to ensure patients have the capability of administering their own therapies using complex medical technology safely and without clinic supervision (p. 28).

Suitability of the Home/ Patient's Willingness to Change the Home

Not all dialysis patients have accommodations that are suitable for home dialysis. Giles (2003) points out that renters, people who live in shelters, and those who pursue various other forms of shelter will experience severe obstacles to receiving home dialysis.

In some countries, such as Australia, New Zealand, and Canada, plumbing and electrical alterations to the home are necessary to install the HHD equipment. For potential HHD patients who rent, approval from the renting agency or property owner must be received, and some assurance must be provided that the patient doesn't intend to relocate in the near future. Proper power circuits, water sources, and water quality must be adequate, and waste disposal systems with backflow protection must be in place (Agar, 2008).

Jennette et al. (2009) find that changes to the home water system and needing a room big enough for the machine and supplies were identified as barriers for HHD. Storage space for PD supplies can be an issue for some patients, since deliveries are rarely feasible more than monthly (Agar, 2008). Hodge (2008) also views inadequate home environment (also reported by Lindley (2006)) as one of the 3 exclusion criteria for HHD, another being unacceptable utility services.

Lehoux (2004) states that dialysis technology does not always fit neatly in the home setting, and describes one PD patient who planned to have an evacuation system installed so he would not have to dispose of the solution from his peritoneal cavity through the toilet anymore. Some patients are reluctant to make changes to their home or make space for supplies, as they don't want to "hospitalize" the home (Giles, 2003; Masterson, 2008, p. S16; Munasque, 2010).

Patients in long-term care facilities (nursing homes) may not be eligible for home therapy due to lack of staff support. In Ottawa, there are no long-term care (LTC) facilities willing to accept patients on PD. PD patients who require admission to a LTC facility have to secure a bed in one of the few PD-friendly facilities outside the city limits, or switch to in-center hemodialysis.

Cultural Issues

Some cultural differences between families and staff regarding expectations can occur. For example, Palmer notes cultural differences in "meeting the standards of time and measurements involved in dialysis, as these were not important considerations in their own society" (1978, p. 377). Palmer explains that "…families might learn the regime easily, but follow it casually, in keeping with the easygoing and fatalistic orientation of their own culture" (p. 377). Social workers can help mediate conflicts between patients' needs or values and medical expectations. Other patients may find the need to dispose of waste products to be disagreeable because of their backgrounds or cultures. The expectation that home dialysis patients will have a stable, long-term residency runs counter to some cultural traditions where frequent changes in residence and fluidity of the family constellation are the norm.

Language Barriers

Lindley (2006) reports that language problems were identified as a barrier to self-care. Cafazzo et al. (2009) report that the patient's level of educational attainment does not appear to be a factor in adoption of NHHD, and that English as a second language does not appear to be a barrier. The barriers occur when the patient's grasp of English (and, in many parts of Canada, French) is minimal. Interpreters and family members or friends can assist in the training process. The bigger barrier is the ability to communicate with on-call staff when patients require urgent assistance with problems at home.

Unplanned Start on Dialysis

A significant number of dialysis patients begin treatment on an urgent basis, with little or no education about kidney disease and treatment modalities. At the Ottawa Hospital in 2010, only 8% of patients receiving their first dialysis treatment had a planned start. While a significant number of these patients were no longer on dialysis at the 3 month marker (due to recovery of kidney function or mortality), the 34% who remained on dialysis were all receiving in-center hemodialysis (The Ottawa Hospital, 2011).

Given that an urgent start almost always entails hemodialysis with a CV line, it is no surprise that "an unplanned start to dialysis seems to be the greatest barrier to the uptake of self-care therapies" (Lindley, 2006), as patients quickly become dependent on dialysis center staff. One solution is a more aggressive approach to educating health professionals about the symptoms of kidney disease, promoting early referrals to nephrology specialists, and enabling quick integration of home dialysis programs.

In-center Dialysis versus "Home First" Policy

In Finland, the pre-dialysis program started in Helsinki made a fundamental change in promoting the ideology of self-care by developing a "home first" policy. The role of the patient changed from passive patient to care provider, and arranged for centralized HHD training that also serves more remote hospitals, report Honkanen and Rauta (2008). They explain that patients prefer to start dialysis directly in the training unit. If there are no contraindications and patients accept, they are directed to either PD or HHD, which are the first-line therapies of choice. The authors also discuss considerations for the future, as the patients starting dialysis are getting older and increasingly have various comorbidities, which means that training times may need to be extended and that patients may need to utilize the backup of dialysis units. Therefore, these authors report, there is a need to put more emphasis on developing systems for assisted treatments, not only for PD, but for HHD as well.

The Ottawa Hospital has an in-center nocturnal hemodialysis program and is starting a self-care hemodialysis unit, where patients can take most of the responsibility for their treatment, yet enjoy the security of nursing support. It is hoped that hemodialysis patients can then transition more easily from hospital-based self-care treatment to home dialysis.

Loss of Relationship with Staff and Other Patients

An issue for patients who start hemodialysis in-center is that after having adjusted to a dependent role, switching to PD or HHD may bring another period of adjustment—this time to a more independent lifestyle (Brey & Jarvis, 1983). Patients who dialyze in-center have the opportunity to socialize a number of times a week, and those who have been on hemodialysis five or more years have spent so much time in the dialysis unit that "contact with [other or outside] friends and family will have filtered away" (p. 204). Masterson (2008) indicates that some patients may feel socially isolated on home dialysis if they have had the experience of in-center dialysis, as they will miss the companionship and support of other patients. In contrast, Agar (2008) finds that patients do adjust, and that they rarely go back to in-center dialysis due to loss of relationships.

Peer support is identified by Wong et al. (2009) as very important during training for NHHD, due to the desire to learn from other patients. These authors state that watching others struggle and achieve their goals helped motivate patients in training, reassured them that they were normal, and reassured them that feeling overwhelmed during their transition to nocturnal HHD was common. This speaks to the importance of early intervention to identify and support potential home therapy candidates.

Support from Staff for Home Dialysis

Jennette et al. (2009) report a finding from Bernadini in 2004 that both patients and dialysis center staff believed myths about PD, including perceptions that PD is inappropriate for patients who are noncompliant or obese, that it demands that patients be totally independent, has poor survival rates, and high infection risks.

Research has found biases in selection criteria, meaning some individuals who could do well at home—or are doing poorly on in-center treatment—are never given the option (Schatell, 2007). Schatell (2007) identifies that patients who are married, of higher socioeconomic status and more educated were more likely to be given modality choices. Schatell discusses the importance of patient-led modality choice, and states that it significantly predicts longer survival and a better chance for transplant than a team-led or even a joint decision. However, the decision about suitability for home dialysis is often made by health professionals without patient consultation. It is important to provide information in an unbiased way, "giving the pros and cons for both PD and HD relevant to their age and comorbidities" states Brown (2008, p. S70). This author adds that most education occurs during the pre-dialysis phase when mild cognitive impairment and uremia may make it difficult for patients to understand the implications of information, and those starting dialysis urgently may never receive this information at all. "It may be appropriate to offer choice of modality 2–3 months after starting dialysis, once patients know more about the ups and downs of life on dialysis" (Brown, 2008, p. S70). This advice contradicts Palmer (1978) who warns about patients becoming "entrenched in the sick role" and reluctant to consider home dialysis.

Empathy from the clinician was found to impact the ability to persevere when learning how to perform NHHD while also dealing with family responsibilities, state Wong et al. (2009). They emphasize the importance of understanding patients' learning styles, as patients distinguish between understanding and memorizing what they were taught. Patients want to gain understanding of why they are required to learn particular concepts and their importance, which Wong et al. (2009) think could be driven by their need for reassurance. They report that different techniques may be required in order to achieve the best learning outcomes, due to the different learning styles. For example, some patients are visual learners and want video material, while others need a varied delivery, such as video coupled with hands-on learning. "Complex and multidimensional learning is challenging, even under ideal conditions, but the challenge is exacerbated by the added responsibilities of coping with an illness and dealing with increased levels of anxiety," which is important to consider when planning patient education and training (p. 32).

Additionally, "a multidisciplinary team approach allowing the patients access to psychosocial counseling may be beneficial in providing support to patients and to their families, while adapting to the training process for home self-treatment. The need for support may become more pervasive as patients and their families assume more responsibility for administering their own treatments" (Wong et al., p. 32).

Knowledge Barriers

Cafazzo et al. (2009) note that "pre-dialysis patients had difficulty articulating their opinions on modality choice as they had little knowledge of the specifics of the various dialysis options. Their lack of experience and knowledge of the different therapies limited their participation in the qualitative study" (p. 788).

The way in which information about HHD is delivered to patients and families can make a difference, which points to the need to have well-trained staff capable of using simple explanatory language devoid of medical terminology as much as possible, states Agar (2008). The author also reports that patients who are secure with dialyzing at home can be a valuable resource to a home dialysis education program. At the Ottawa Hospital, home dialysis patients are being recruited to participate in the education of pre-dialysis patients. In addition, the hospital has a dedicated nurse-educator who meets with in-center hemodialysis patients as well as their families to discuss the option of home dialysis, and admits patients who require an acute start.

Hodge (2008) states that physician-patient discussion should focus on expected clinical outcomes and health benefits, not patient convenience or "lifestyle" (p. 1). The author explains that the "financial health of dialysis centers will be enhanced by shifting continually inflating costs from the center to the patients and home caregivers." This sounds simplistic as it does not consider the psychosocial aspects involved in performing dialysis at home, which are crucial to patient satisfaction and adherence to the home dialysis program. However, we must acknowledge that patients and family members who have more information about the health benefits of more frequent dialysis may then be willing to make some changes to their lives to accommodate home dialysis.

Lehoux (2004) conducted a qualitative study documenting patients' perspectives on how the user-friendliness of home care technology influences its integration into their private lives. Lehoux studied four types of home care interventions, one of which was PD (sample size = 3 patients). The conclusion by this author is that patients rarely perceived home care technology to be user-friendly, and user acceptance was closely linked to user competence. Therefore it is important to consider lengthening the training period until the patients have more confidence in being able to master the machine.

Cost to Hospital/Availability of Staff to Train and Maintain Home Dialysis Patients

Hodge (2008) proposes a trial during which patients dialyze more frequently in-center to demonstrate whether patients have enough self-discipline to justify the expense of training. In some centers, identified barriers to home dialysis are: lack of time for training and monitoring patients, lack of space for training, lack of support from doctors, as well as economic pressure to keep the hemodialysis center running to capacity (Lindley, 2006). In fact, Kalirao and Kaplan (2009) discuss the higher direct cost of nocturnal home hemodialysis for centers in Canada. Reimbursement is established for conventional hemodialysis at three times per week. However, significant savings were shown in many other areas: staff, medications, support, hospital admissions, and procedures—with the projected annual saving of $10,000 less per patient than in-center HD (p. 259). The lack of dedicated resources is one of the main barriers to the growth of home dialysis, especially when converting patients who are used to full-time care, despite simplification of the dialysis procedures and evidence of improved outcomes (Ledebo, 2008). The author states that organizational expectations for the number of patients using home dialysis should be based on patient capabilities, not organizational shortcomings.

Cost to the Patient

"In some Australia and New Zealand states, an annual reimbursement from the state assists patients with any costs incurred through the provision and use of standard utilities—particularly water and power costs [in the home]" (Agar, 2008).

At the Ottawa Hospital, the home dialysis team assisted in advocating for an annual water bill rebate from the city of Ottawa, which is now available to all HHD patients living within city limits. As of this writing, the city of Ottawa and a municipality on Vancouver Island are the only areas in Canada that have established an annual water rebate for patients on HHD. To date, there is no assistance with power costs.

Agar also mentions that training for both PD and HHD is less developed in the U.S. due to the cost burden to patients, whereas it is fully funded by the state in ANZ. This is also the case in Canada, where there is universal health care and access to a federal program of unemployment health insurance benefits.

REVIEW OF TOOLS

The Jo-Pre-training Assessment Tool (JPAT) was developed in 1996 (Chow & Bennett, 2001). It is a quantitative assessment of a person's suitability for HHD or PD. Prior to developing this tool, the authors had not found another tool purposely designed to assess potential candidates before they start training for home dialysis. They felt that it was important to assess the person prior to starting training, so he or she would be in a better position to make informed decisions about health care. The content of the JPAT was determined from a consensus of a focus group (expert opinion), a literature review, a telephone survey, and a 1996 national survey of 36 renal units and a review of their pre-dialysis training assessment methods. A pilot study served to refine the instrument before its use in ESRD programs.

The JPAT is primarily focused on identifying health-related problems (e.g., bowel problems, hypertension, nutritional status, and physical stability) that may affect home dialysis therapy, but also addresses some psychosocial issues (e.g., living arrangements, mental status, motivation, and sense of control). Interviews are conducted with patients based on 38 assessment items in 6 domains: Physical Stability, Nutritional Status, Communication Ability, Ability to Maintain Self-Care, Social Support, and Psychological Suitability.

The tool is based on the Medical Outcomes Study Short Form 36-Item Health Survey (SF-36®), by McHorney, Ware, and Sherbourne (1994). Guided by the SF-36, Chow and Bennett (2001) looked at items, such as the section entitled "Physical Functioning and Role Limitation Due to Physical Health," which may partially apply to assessing a person's ability to maintain self-care, e.g., lifting, carrying groceries, climbing stairs, bending, bathing, and dressing. The interviewers are also required to observe activities such as hand-eye coordination. Results from the pilot study showed that patients who currently worked around the house were likely to be home therapy candidates. The JPAT has proven to be a reliable tool for use with ESRD patients in Australia, "identifying patients with the greatest chance of learning to manage the program" (Chow, 2005, p. 19). Chow & Bennett (2001) also found that it was useful in assessing patient conditions and needs before starting the dialysis training, as well as for ongoing assessment of current dialysis patients' physical and mental status.

Agar (2008) references the Method to Assess Treatment Choices for Home Dialysis (MATCH-D), which was developed by Schatell and Witten in 2007 with the input of American, Canadian and Australian home dialysis experts. The author indicates that a valid approach is to consider that people with the skills to drive or use a sewing machine should be, by definition, potential HHD candidates. Schatell (2007) explains the rationale for the MATCH-D tool, which was designed to standardize the selection criteria and avoid biases in patient selection for referral, as identified in research. The author mentions the characteristics of the ideal home dialysis candidate: working or in school, caring for loved ones, traveling actively, having issues with transportation to in-center treatments, having trouble following the in-center diet and fluid limits, and being unhappy because of lack of control. This tool recognizes that patients who are depressed, angry, or disruptive in-center may actually do better at home. In addition, this tool recognizes the importance of patient motivation. However, patients who don't have a dialysis partner are considered unsuitable for HHD and referred to PD.

Schatell (2007) explains that the MATCH-D tool does not have a point system, as the information is gathered to promote discussion between the patient, family, and care team for the patient to choose the treatment modality that is most appropriate for his or her lifestyle and capabilities. This tool also lists some of the barriers and solutions. MATCH-D helps the care staff identify patients who can succeed at home more independently, those for whom more consideration is needed to overcome barriers, and those who need a helper to take primary responsibility.

CONCLUSION

Throughout this review, we developed an understanding of many reasons why medically eligible patients may decline or never be offered home dialysis, and more importantly, why patients may start and then quit home dialysis. The barriers facing patients on home modalities can easily be taken for granted. Lehoux (2008) points out the need for a "smooth fit" between the technical and human barriers that affect patient compliance. Lehoux indicates that with a growing elderly population and limited health care resources, promoting self-management will become a major issue in most industrialized countries. Home treatment involves more than simply transferring a particular technology from the hospital to the home; it requires transferring knowledge and skills to lay people, and making sure that the home and social environments enable a safe, effective, appropriate, and personally satisfying use of technology (Lehoux, 2004, p. 8).

Improving our understanding of the challenges faced by home dialysis patients and their families can help increase the number of patients using home dialysis. As Wong et al. (2009) note "…it was widely assumed that technology-related fears and concerns posed the greatest potential barrier to the training of patients and caregivers to self-administer HHD. However… [the primary barriers] were psychosocial in nature rather than technological, as originally anticipated" (p. 31). The importance of understanding and ameliorating the very real emotional and social challenges faced by both patients and their families is key to increasing the home dialysis rates.

The point of assessment is to not only gather information about the patient, but also to engage the patient and caregiver in additional learning about the practicalities of performing dialysis at home. The assessor is provided with an opportunity to gain insight into the patient's values and priorities, and to engage in problem solving with the family and the medical team. Social workers have a very important role to play in assessing and preparing patients for home dialysis, and communicating patients' concerns to the health care team. As Peterson (1984) states: "The nephrology social worker is the only member of the treatment team whose professional orientation is geared towards the psychosocial management of chronic renal failure" (p. 42). With knowledge of the social stressors faced by patients and families, and skills at facilitating patient empowerment, social workers can help patients transition from passive recipients of medical care to active participants in the kidney health care team.

The literature indicates that a patient's ability to manage the psychosocial aspects of home dialysis is a significant predictor of success (Peterson, 1984; Wong et al., 2009). While the JPAT and MATCH-D tools address some of the psychosocial elements of home dialysis, the authors ask if a more in-depth psychosocial assessment could improve patient selection and patient readiness for home dialysis. To this end, we are developing a psychosocial assessment tool for patients with no medical contraindications to PD or HHD: the Psychosocial Assessment Tool for Home Dialysis (PATH-D). We see the need for a tool developed by social workers with the specific intention of assessing social or attitudinal barriers which can prevent seemingly ideal candidates from succeeding with home dialysis. The PATH-D is still under development, but we hope further study validates that a thorough psychosocial assessment can assist in developing strategies to reduce social barriers, better preparing patients for the realities of home dialysis, and matching patients to the most sustainable treatment modality according to their abilities, lifestyles, and social support.

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The Impact of State Budgets on the Kidney Industry and People with ESRD

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While the economy in the United States is improving, states continue to struggle to balance their budgets. Over the past several years, negative effects of budget reductions have been experienced by people with end-stage renal disease (ESRD) and dialysis providers. This article explores the varied reductions, their impact on people with ESRD and dialysis providers, and describes advocacy efforts. Coalitions are especially valuable in advocating for continued funding of benefits and services related to ESRD.

INTRODUCTION

Although the recession seems to be ending and the economy improving, states continue to struggle to balance their budgets. According to a state fiscal survey conducted by the National Governors Association (NGA) and the National Association of State Budget Officers (NASBO), states have implemented $60 billion in reductions in the past two years to close their budget gaps. They have also used "rainy day" funds and have raised $30 billion through increased taxes and fees (National Governors Association, 2010). Nearly every state implemented at least one new policy last year to help control Medicaid spending. The Kaiser Commission on Medicaid and the Uninsured produced its annual report on state Medicaid agencies, and found several common trends (Kaiser Commission on Medicaid and the Uninsured, 2011). First, some Medicaid benefits were restricted, the most common being prescription drugs, dental coverage, medical supplies, nutritional supplements, and podiatry services. Second, states implemented cost savings related to Medicaid beneficiary financial responsibilities. Nineteen states have increased copays for Medicaid beneficiaries in the last two years, particularly for prescription drugs for adults. Third, provider reimbursement rate reductions for Medicaid were common and the easiest to implement.

MEDICAID PROVIDER RATE REDUCTIONS

Provider rate reductions were the most commonly used cost containment strategy for state Medicaid programs. Provider rate reductions produce instant savings, so Medicaid providers are especially vulnerable in difficult financial times. In 2011, 13 states implemented Medicaid provider rate reductions related to payments for dialysis treatments (see Table 1). Nationally, the dialysis industry estimates that approximately 5 to 10% of Medicaid beneficiaries who receive dialysis treatments rely on Medicaid as their primary insurance and will not be eligible for the Medicare benefit. An additional 35 to 45% of Medicaid beneficiaries with kidney failure are “dual eligibles”—that is, they have Medicare as their primary insurance and Medicaid as their secondary payer. This high percentage of Medicaid beneficiaries, combined with the frequency of dialysis treatments, leaves dialysis providers at higher risk for a loss of operating revenues than other medical providers when there are Medicaid reimbursement reductions.

As a result of that payer mix, many dialysis facilities are vulnerable to operating in a negative margin, which threatens their ability to continue to provide care. Industry analysis has found that dialysis units operating in a negative margin are generally those with a higher population of individuals relying on Medicaid for their health insurance. The most vulnerable facilities could be at risk for consolidation or closure if providers experience further payment reductions. Facility closures also result in job loss and increased unemployment for the state. For dialysis patients, facility consolidations or closures could mean increased driving distances to treatments, and a change in physicians and care teams who are aware of their specific health needs. Dialysis clinics become communities of their own, which would be disrupted for both patients and staff if they close. Many, if not most, dialysis provider companies try to support vulnerable facilities in order to keep facilities where the need is high.

Table 1 shows the Medicaid provider rate reductions implemented in 2011. In each state, dialysis providers, patients, and patient organizations advocated by meeting with Medicaid officials, communicating with state legislators, and, in some states, by sending letters to the Centers for Medicare and Medicaid Services (CMS) in their oversight capacity with regard to state Medicaid programs. Meetings between state legislators and dialysis providers included local employees and focused on the negative impact to patients and communities if facilities would be forced to close. Advocates also highlighted any evidence of disproportionate impact on the industry, meaning that dialysis providers would be more impacted by cuts than other types of medical providers, due to serving Medicaid beneficiaries three times a week and having a higher percentage of Medicaid patients.

In April 2011, Texas Medicaid threatened to discontinue paying secondary Medicaid payments for all people who were dually eligible for Medicare and Medicaid. This would have represented a 20% loss of revenue from over 35% of all dialysis patients. Hundreds of letters from dialysis facility staff (including social workers) and dialysis patients were sent to state legislators. Meetings were held with Medicaid officials to educate them on the dialysis industry and the impact the cuts would have on continued operations. Dialysis patients spoke with the legislators about the negative impact on them if specific facilities would close. The state recognized that dialysis providers would experience a more negative impact than other types of medical facilities. The final budget bill ended up including an exemption for dialysis providers, resulting in continued funding of secondary insurance. They did decrease the Medicaid primary and secondary payments by 5%; however, the overall payment was left intact.

Table 1. *2011 Medicaid Provider Rate Reductions to Dialysis Payments*

State	Proposed Reduction and Outcome
Arizona	The Centers for Medicare & Medicaid Services (CMS) approved a 5% Medicaid primary rate reduction to providers that was passed by the state legislature; it was effective October 1, 2011. Reductions in nonemergency medical transportation were proposed, but were left intact; however, a transportation copay will begin for people who live in Maricopa and Pima counties.
California	The state legislature passed a 10% Medicaid primary rate reduction to providers, an increase in beneficiary copays, and limits to drugs and outpatient visits, effective June 1, 2011 (dialysis patients are exempt from the copays and the 7-visit limit for outpatient visits). CMS approved the 10% Medicaid reduction; a group of health providers has filed a lawsuit. The Supreme Court refused to rule, so it is back to the lower courts to decide. Nutritional supplement benefits were reduced—only beneficiaries with specific health diagnoses will qualify.
Massachusetts	The state is proposing an all-inclusive rate of $190.74 per dialysis treatment, which includes payment for costs of all MassHealth-covered routine drugs, lab tests, home dialysis supplies, and all other dialysis-related services. It includes an add-on of $20 per session for home dialysis training.
Minnesota	The state's proposed budget called for elimination of Medicaid secondary payments for dual eligibles since Medicare rates would exceed Medicaid rates; however, Medicaid secondary payments were preserved. The state reduced Medicaid primary rates to providers by 3%, effective September 1, 2011.
North Carolina	The state budget included a 2% across-the-board reduction to the Medicaid primary rate for all providers, beginning October 1, 2011. The reduction has been implemented.
Nevada	The governor's proposed budget included a 15% Medicaid primary rate reduction to providers, including dialysis. Dialysis providers succeeded in being included on an initial list of providers exempt from the proposed reduction. However, the governor's budget did not get accepted by the state legislature, so all providers that were exempt ended up getting the 15% reduction, effective July 1, 2011.
Ohio	The governor's proposed two-year budget plan included the elimination of Medicaid secondary payments for dual eligibles since Medicare rates would exceed the Medicaid rates. After meetings with dialysis providers, Medicaid will continue paying the secondary payments for 2011. It will be at risk in 2012.
Oregon	The governor's proposed budget initially included a 19% Medicaid primary rate reduction to providers. The state legislature passed an 11.2% Medicaid primary rate reduction to providers, effective July 1, 2011 (does not include Medicaid managed care providers).
New Jersey	The state initially proposed an all-inclusive rate of $176 per treatment per dialysis treatment. After input from dialysis providers, the state settled on an all-inclusive rate of $281.85 per treatment.

State	Proposed Reduction and Outcome
New York	The state implemented a 2% Medicaid primary rate reduction to providers, as of April 1, 2011. The state also proposed eliminating Medicaid secondary payments for dual eligibles, as Medicare payments would exceed Medicaid rates. New York Medicaid officials are in conversation with dialysis providers and have not yet implemented the elimination of Medicaid secondary payments.
South Carolina	The state implemented a 3% across-the-board Medicaid primary rate reduction to providers effective April 1, 2011. An additional 7% reduction was implemented July 1, 2011.
Texas	A 2% Medicaid primary rate reduction to providers was made, effective February 1, 2011. An additional 5% Medicaid primary rate reduction was implemented on September 1, 2011. The state also proposed eliminating Medicaid secondary payments for dual eligibles, but exempted dialysis providers from the reduction. A 5% reduction to Medicaid secondary payments was implemented January 1, 2012.
Wisconsin	The state moved to an all-inclusive Medicaid primary rate of $183.70 per treatment, effective September 10, 2011, and eliminated Medicaid secondary payments for dual eligibles. After meeting with dialysis providers the state reissued its bulletin with a temporary all-inclusive rate of $214. The state is working with providers to determine an acceptable permanent rate.

IMPLEMENTATION AND EXPANSION OF MEDICAID MANAGED CARE

States are also implementing or expanding cost savings through Medicaid Managed Care plans. Twenty-four states plan to expand or begin Medicaid Managed Care plans in 2012. States are using managed care as a way to implement quality and performance programs and for cost containment. Whereas in the past, states mainly focused on enrolling those with Medicaid as their primary insurance into new Medicaid Managed Care plans, more states are also beginning to enroll people who are dual eligibles (those with Medicare and Medicaid).

The kidney industry has seen some problems as states transition to Medicaid Managed Care either too quickly or without enough preparation. For example, in California some ESRD Medicaid beneficiaries were defaulted into managed care plans with primary care physicians who were a long distance away or who had no affiliation with their attending nephrologists or dialysis facilities. Authorization for services then had to be obtained from a physician who had no knowledge of the patient. Medicaid Managed Care plans have been slow to contract with dialysis providers in some areas or providers have been excluded from networks within contracts. The California Dialysis Council (CDC) is informing state legislators and Department of Health officials that people with ESRD have a high need for care coordination due to the following factors:

- A high rate of comorbid conditions
- The need for treatment coordination between Medicaid Managed Care plans, physician groups, transplant centers, dialysis providers, vascular surgeons and nephrologists to ensure continuity of care
- Transplantation is best for the patient and saves money for the state Medicaid program. However, those patients who are appropriate for and want to pursue transplantation have an additional need for coordination between Medicaid Managed Care plans and transplant centers.
- Transportation to dialysis treatments is vitally important and must be included as a benefit in the Medicaid Managed Care plan in a way that allows dialysis providers to work with transportation companies to ensure an appropriate level of service for this population.

The CDC is seeking to introduce state legislation this year that will allow ESRD dual eligibles a longer transition time to enroll in a managed care plan if their physician, dialysis provider, or transplant program certify that a risk to their continuity of care exists if people with ESRD enroll without necessary resources in place. Dialysis social workers have been directly involved in advocacy efforts by contacting state legislators and documenting adverse effects.

STATE RISK POOLS AND STATE KIDNEY PROGRAMS

Additional programs that have experienced negative effects of state budget reductions are state risk pools and state kidney programs. Over 30 states currently have high insurance risk pools that are administered through state funding, grants, and/or insurer assessment fees. The purpose of state risk pools is to provide health insurance to those who are unable to qualify for health insurance due to preexisting health conditions. Washington State proposed to eliminate its risk pool when it starts its health insurance exchange, which would provide coverage for those with pre-existing conditions in 2014. This would be a problem for dialysis patients who currently access the risk pool for Medicare supplement policies, since Medicare supplements are not offered in the new health insurance exchange programs. Washington dialysis providers and national dialysis patient organizations quickly formed a coalition to respond. Members of the coalition attended state risk pool board meetings to bring the issue to the board's attention. State legislators were contacted and asked to amend the existing legislation to allow the risk pool to continue. Through advocacy by the kidney community, the state's legislation was amended to include a study of the state's risk pool to be conducted by the end of 2012. It is hoped that, through this study, the state will decide to continue its risk pool after 2014 when the health insurance exchange is implemented.

Twenty-one states currently have state kidney programs, which exist through state funding and offer education and charitable assistance to people with kidney failure. A list is available at **http://som.missouri.edu/mokp/docs/noskp/index.html.** Some state kidney programs have seen reductions in funding or have been eliminated altogether. Missouri's kidney program received a $1.5 million reduction in its funding during the 2011 legislative session. In March 2012, the Idaho legislature passed a bill to terminate its kidney program as of July 1, 2013. The kidney community mobilized in both of these situations and contacted legislators to raise awareness of the value of the state kidney programs. More advocacy will be done in the future to try to restore funding and programs.

ON THE HORIZON: HEALTH CARE EXCHANGES

On June 28, 2012, the United States Supreme Court released its decision on the areas of the Affordable Care Act (ACA) under its consideration. The Court ruled that the individual mandate, which requires most Americans to purchase health insurance or pay a penalty beginning in 2014, is permitted under the Constitution. The Court upheld the law in its entirety except that the Federal Government cannot deny a state's Medicaid funding if the state does not participate in the law's Medicaid expansion. Beginning in 2014, the ACA expands the Medicaid program's mandatory coverage requirements to include childless adults under age 65 up to 133% of the federal poverty level (blind, aged, disabled, and those on Medicare are excluded) (Patton Boggs, LLC, 2012).

According to the Affordable Care Act, health insurance exchanges must be ready by January 1, 2014. The exchanges are intended to be an online marketplace for health insurance. States can create their own exchanges, work with other states to create regional exchanges, or choose to have the Federal Government run the exchange for their state. The exchanges will enable people without insurance and small businesses to "shop" for insurance. Half of the uninsured will be covered by the ACA expansion of Medicaid; applicants for insurance in the exchanges will be directed to Medicaid if they are eligible (Kaiser Health News, 2011).

Most people will continue to access health insurance through their employers, Medicare, or Medicaid. Under the ACA, those who earn less than 133% of the federal poverty level ($10.809.23 x 1.33 = $14,484 in 2012) will qualify for Medicaid. The ACA does not address secondary insurance coverage of any kind, so exchanges do not include Medicare secondary insurance (Medigap) policies. Undocumented immigrants will not be allowed to purchase insurance through an exchange.

Those accessing insurance through the exchanges will include:

- Individuals buying their own coverage
- Employers with fewer than 100 employees (50 in some states)
- Members of Congress and their staff who will be required to buy insurance through the exchanges if they want coverage through the Federal Government

Employers with more than 100 employees may be able to access the exchanges after 2017 (Kaiser Health News, 2011).

The Congressional Budget Office estimates that, from 2016 on, between 20 million and 23 million people will use the exchanges (Congressional Budget Office, 2012). Most will be eligible for premium subsidies, at an estimated average of $4,000 per person in 2014. Sliding scale subsidies will be available for those who earn up to 400% of the poverty level, about $43,560 in 2011 (Congressional Budget Office, 2009). Between the existing options for insurance coverage and the new health insurance exchanges, most people will be required to have health coverage of some sort beginning in 2014.

The health insurance exchanges, like many issues these days, have become embroiled in politics. Forty-nine states (all but AK and MN) and the District of Columbia received exchange planning grants to help them establish their exchanges. Two states (FL and LA) returned their planning grants, while three states (KS, OK, and WI) have returned their early innovator grants, which were awarded to a small number of states to create health information technology systems for exchanges (Henry J. Kaiser Family Foundation. State Health Facts, 2012). The grant returns were a result of pressure from lawmakers to block implementation of the ACA. Governor Sam Brownback (KS) cited a desire for less reliance on federal assistance as a reason for returning Kansas' grant, and stated that the grant had too many strings attached (Kansas Health Institute, 2011). A federal appeals court previously ruled that Congress does not have the power to require Americans to buy health insurance. Delays in implementation of various aspects of the ACA are anticipated due to short time frames for states that have not embraced the ACA, additional lawsuits, or congressional actions that will try to delay or repeal the ACA.

HEALTH CARE REFORM AND THE KIDNEY INDUSTRY

While the kidney community did not advocate against health care reform, there are issues in the Affordable Care Act of which the kidney community should be aware. The ACA law was unclear about whether the Medicare Secondary Payer (MSP) law (defines when Medicare becomes the primary payer) would apply to individuals with employer group health coverage accessed through the new exchanges. Absent MSP, individuals who develop kidney failure would have Medicare coverage at 90 days, and therefore would be unable to participate in a group policy through the health insurance exchange. In March 2012, the United States Health & Human Services (HHS) issued its final rule on the health insurance exchanges and clarified that the MSP law will apply to group policies in the health insurance exchanges. Therefore, people who have a group policy through a health insurance exchange and then become diagnosed with ESRD have the choice to continue their policy for 30 months after becoming eligible for Medicare—just like the MSP law currently works. The kidney industry was pleased with this outcome; much advocacy had been done with HHS, the Centers for Medicare & Medicaid Services (CMS), Members of Congress, governors, state legislators, and insurance commissioners to raise awareness of this issue. Kidney coalitions in Kansas, Florida, and California wrote letters to HHS, and state legislators, insurance commissioners, and some governors wrote letters to HHS on behalf of the dialysis industry. State officials were motivated to contact HHS because if the MSP law did not apply to the health care exchanges, there could be more people accessing Medicaid for the 90-day Medicare waiting period if they could not continue to have insurance through the exchange. This would cause increased costs for the states.

Many people purchasing insurance through the exchanges will be eligible for financial assistance for their monthly insurance premiums based on their income. Those premium subsidies end when they become eligible for other health care programs, such as Medicare. If they cannot afford to continue their insurance coverage, they will default to the Medicare ESRD benefit. These changes would increase costs to the Medicare program, and dialysis providers will become even more dependent on Medicare revenue. The kidney industry is currently evaluating the most effective ways to advocate for ESRD beneficiaries to continue to have access to premium subsidies, even if they qualify for Medicare.

An important concern at the state level is the desire for adequate provider networks in the exchange plans that can meet the needs of individuals with kidney failure. All of us should watch our own state news for information about health insurance exchange development as well as opportunities to share concerns or support and to educate government health planners about the needs of those with kidney disease. These opportunities could include serving on your state's exchange implementation committee or attending public meetings to learn more and offer your own comments.

CONCLUSION

While the outcomes have not always been successful, it is important that the kidney community continue to advocate for the insurance needs of people with ESRD, and for dialysis providers to be able to have adequate funding through benefits. Since 2003, national coalitions such as Kidney Care Partners and the Kidney Care Council have formed to advocate on federal issues. Several states, including California, Florida, Ohio, and Kansas have organized state-level kidney coalitions. In other states, short-term coalitions have formed around specific issues. These coalitions are extremely valuable as they are a way to bring the industry together around common concerns and to speak with one voice to legislators and government agencies. Social workers must continue to use their advocacy skills to speak on behalf of people with ESRD and their dialysis providers who may be vulnerable to the negative impact of state budget reductions.

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Psychological Symptoms and End-of-Life Decision-Making Confidence in Surrogate Decision Makers of Dialysis Patients

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This cross-sectional descriptive study explored surrogate decision makers' psychological symptoms and their own assessment of decision-making abilities before actual involvement in end-of-life decisions for their loved ones. One hundred twenty dialysis patients' surrogates (79 African Americans and 41 Caucasians) completed scales measuring decision-making confidence, anxiety, depression, post-traumatic stress symptoms (PTSS), and a sociodemographic questionnaire. Forty-two (35%) and 14 (11.7%) surrogates showed abnormal scores on the anxiety and depression scales, respectively. Seven (5.8%) surrogates showed abnormal scores on the PTSS scale. While surrogates' decision-making confidence was high ($M = 17.70$, $SD = 2.88$), there was no association between decision-making confidence and the three psychological variables. Surrogates' confidence was associated only with the quality of their relationships with patients ($r = 0.33$, $p = 0.001$).

INTRODUCTION

Surrogate decision makers, individuals who have been designated as health care agents for others, are expected to make medical decisions on behalf of other people who are not capable. Typically, these decisions are complex and can cause emotional distress for the surrogate decision-makers, particularly when end-of-life treatment decisions are involved (Wendler & Rid, 2011). For example, symptoms of anxiety, depression, and post-traumatic stress are common in surrogates who have experienced difficult decision making for their loved ones, such as decisions to limit life-sustaining treatment (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Braun, Beyth, Ford, & McCullough, 2008; Hebert, Schulz, Copeland, & Arnold, 2009; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008; Tilden, Tolle, Nelson, & Fields, 2001). Even at 6 to 12 months after patients' deaths, family members and other surrogates experience intrusive thoughts of regret or search for evidence that they made the right decision (Braun et al., 2008; Hansen, Archbold, & Stewart, 2004; Shiozaki et al., 2008; Tilden et al., 2001; Wright et al., 2008).

Much of the current literature calls for interventions to support surrogates prior to and/or during the decision-making process so that negative psychological effects may be reduced (Hebert et al., 2009; Wendler & Rid, 2011). If surrogates of patients with serious chronic illness are already experiencing psychological symptoms (e.g., anxiety and depression symptoms), this may predispose them to substantial psychological distress *after* end-of-life decision-making experiences (Siegel et al., 2008). Yet, surrogates' psychological status and their own assessment of their decision-making abilities before they are involved in end-of-life decision making have received little attention.

The purpose of this study was to explore the relationships among surrogates' psychological variables, sociodemographic characteristics, and end-of-life decision-making confidence using a sample of dialysis patients' surrogates who had not yet engaged in end-of-life decision making. Specifically, we addressed the following aims: 1) to describe the psychological symptoms and end-of-life decision-making confidence of surrogates who are likely to make treatment decisions on behalf of dialysis patients; 2) examine the association between surrogates' psychological symptoms and decision-making confidence; and 3) explore surrogates' sociodemographic characteristics, including race/ethnicity (non-Hispanic African American or non-Hispanic Caucasian), that are associated with their psychological symptoms and decision-making confidence.

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METHODS

Design and Sample

We used baseline data from 120 dialysis patients' surrogates who participated in a randomized controlled trial to test the effect of an end-of-life communication intervention on patient and surrogate decision-making outcomes over 12 months post-randomization. Patients were eligible for the parent study if they met the following criteria: self-identified African American or Caucasian, receiving dialysis for at least 6 months prior to enrollment, Charlson Comorbidity Index (CCI) (Fried, Bernardini, & Piraino, 2001) score ≥ 6 or CCI score = 5, and having been hospitalized in the last 6 months (criteria associated with an estimated 30% one-patient year mortality) (Charlson, Szatrowski, Peterson, & Gold, 1994; Fried et al., 2001; Fried, Bernardini, & Piraino, 2003). The CCI includes 19 comorbid conditions, including myocardial infarction, congestive heart failure, AIDS, cerebrovascular disease, and liver disease. A higher score indicates a greater risk of mortality (Charlson et al., 1994; Fried, et al., 2001, 2003). In addition, patients had to have an English-speaking surrogate over age 18 who could participate in the study with the patient.

Patients were recruited from 15 outpatient dialysis centers in 9 counties in North Carolina. Social workers at the dialysis centers approached potential patient participants to assess their interest in the study after confirming that they met the criteria of race, age, and months on dialysis. The research staff reviewed medical records of 610 potential patient participants to further assess their eligibility and approached the patients for informed consent and a cognitive screening test, the 10-item Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975). Patients with > 2 errors on the SPMSQ (e.g., abnormal cognitive functioning) were deemed ineligible.

Of the 249 eligible patients, 159 (63.9%) consented to join the study. After patient consent was obtained, the research staff contacted their surrogates and invited them to join the study if they were over 18 years old, able to speak English, and willing to participate in the intervention with the patients. Of the 159 surrogates invited, 120 (75.5%) provided written consent to participate in the study.

Measures and Data Collection

The study procedures were approved by the Institutional Review Board of the University of North Carolina at Chapel Hill and the clinical trials offices of the participating dialysis organizations. Baseline data were collected over the telephone by the research staff, a process that took approximately 30 minutes. The measures and questionnaires relevant to our research questions are described below.

Decision-Making Confidence Scale (Song et al., 2009; Song et al., 2010).

This scale measured surrogates' confidence in end-of-life decision-making for their loved ones. It consists of five items that have response options from 0 (Not Confident At All) to 4 (Very Confident), reflecting an individual's level of comfort in the role of surrogate (Cronbach's $\alpha = 0.85$ with the study sample). For example, one item is "I feel confident that I understand what my loved one's preferences are." A sum of the 5 items is used for analysis; thus, scores range from 0 to 20.

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983).

This scale measured surrogate anxiety and depression (7 items for each subscale). The scale is not designed to make a diagnosis of a psychiatric disorder, but rather to identify individuals who have symptoms that may require further psychiatric evaluation and assistance. Response options for each item are on a 4-point Likert-type self-report rating scale (0 – 3). Subscale scores for both range from 0 to 21 with the following categories: 0 – 7 = normal; 8 – 10 = borderline abnormal (mild); and 11 – 21 = abnormal (11 – 14 = moderate; 15 – 21 = severe). Reported internal consistencies and test-retest reliabilities are .88 – .90 and .84 – .94, respectively, for each subscale (Lowe et al., 2004; Whelan-Goodinson, Ponsford, & Schonberger, 2009). The scale has been widely used to assess symptoms of anxiety and depression in patients and in family members of patients (Herrmann, 1997; Pochard et al., 2001). For the 120 surrogates in this study, internal consistency (Cronbach's α) was 0.81 and 0.73 for anxiety and depression, respectively.

The Post-Traumatic Symptoms Scale-10 (PTSS-10) (Eid, Thayer, & Johnsen, 1999).

This self-report scale measures the presence and intensity of 10 post-traumatic distress symptoms during the preceding 7 days (e.g., sleep problems, nightmares, tension in the body, irritation, startle), each rated on a 7-point Likert scale from 1 (Never/Rare) to 7 (Very Often/Always). A total score (range 10 – 70) of > 35 is associated with a high probability that the person meets the diagnostic criteria for post-traumatic stress disorder (Weisaeth, 1993). The PTSS-10 has been shown to have high sensitivity and specificity (Eid et al., 1999; Johansen, Wahl, Eilertsen, & Weisaeth, 2007; Schelling et al., 1998). Cronbach's α for this sample was 0.83.

Other Descriptive Data

Other descriptive data included sociodemographic information, such as age, gender, race/ethnicity, years of formal education completed, marital status, annual household income, whether the patient and surrogate reside in the same household, surrogate relationship to the patient, the importance of religious or spirituality in life on a 4-point scale from 1 (Not At All Important) to 4 (Extremely Important), and surrogates' perceived relationship quality with patients using an overall rating in response to "How would you rate the quality of relationship with your …?" from 1 (Poor) to 5 (Excellent).

Data Analysis

Descriptive statistics (i.e., mean, SD, frequency, and percent) were used to summarize sample characteristics; anxiety, depression, and PTSS symptom scores; and decision-making confidence. To examine the bivariate relationships between psychological variables (anxiety, depression, and PTSS scores) and surrogate decision-making confidence, Pearson correlation coefficients were used. To test the significance of the difference between correlation coefficients of African American and Caucasian groups, a z-score was calculated using the Fisher r-to-z transformation with a one-tailed test. The relationships between sociodemographic characteristics and psychological variables, as well as decision-making confidence, were determined using Pearson correlation coefficients, t-tests, and ANOVA, as appropriate.

RESULTS

Characteristics of Study Participants

Table 1 presents surrogates' sociodemographic characteristics. Of the 120 surrogates, 79 (65.8%) were African Americans. The majority of surrogates were female (69.2%), spouses or partners of the patients (44.2%), married (61.7%), and currently living with the patients (62.5%). Fifty-seven surrogates (47.5%) reported a total annual household income of less than $30,000. On average, surrogates' rating of quality of relationship with the patient was 4.39 (SD = 0.75), between "Good" and "Excellent." A majority of the surrogates (94.2%) said that they had lost a close family member or a friend, though only 29.2% were involved in difficult medical decision-making for that family member or friend.

Patients had a mean (SD) age of 62.9 (10.9) years. Seventy patients (58.1%) were 61 years or older, 61.9% were female, and 92.3% were receiving in-center hemodialysis. Patients' median months on dialysis was 32 (range 6 to 296). The mean Charleson Comorbidity Index (CCI) score was 7.40 (SD = 1.7).

Surrogates' Psychological Status and End-of-Life Decision-Making Confidence

Table 2 displays mean symptom scores of anxiety, depression, and PTSS. For all three variables, mean scores were within normal ranges. However, 35% ($n = 42$) and 11.67% ($n = 14$) of surrogates showed a score of 8 or higher on the anxiety and depression scales, respectively. Seven (5.8%) surrogates' PTSS scores were higher than 35.

Table 3 shows that surrogates' end-of-life decision-making confidence was high, with a scale mean (SD) of 17.7 (2.88). For each of the five items within the scale, mean scores were all greater than 3.0, suggesting that surrogates felt quite confident about end-of-life decision making for their loved ones.

In the total sample, there was no association between surrogates' end-of-life decision-making confidence and any of the three psychological variables. Alternatively, within the African American surrogate subgroup, depression symptom scores were inversely correlated with decision-making confidence ($r = -0.24$; $p = 0.049$), but that association was not significantly different from the correlation seen in the Caucasian group ($z = -1.43$; $p_{\text{1-tailed}} = 0.07$), which was close to zero ($r = -0.04$).

Associations Between Sociodemographic Characteristics, Psychological Symptoms, and Decision-Making Confidence

Of the sociodemographic characteristics of the surrogates, gender, years of formal education, total annual income, and overall rating of relationship quality were significantly associated with anxiety, depression, and PTSS symptom scores and decision-making confidence scores (Table 4). Specifically, although the magnitude of the associations was small, years of formal education, total income, and relationship quality were inversely correlated with anxiety and depression symptom scores. Female sex, total income, and relationship quality were also inversely associated with PTSS scores. On the other hand, surrogates' decision-making confidence was positively associated only with the quality of relationship with patient ($r = 0.33$, $p = 0.001$). Patients' sociodemographic and clinical variables were not associated with surrogates' psychological symptoms or decision-making confidence.

DISCUSSION

We examined relationships between psychological status and end-of-life decision-making confidence among surrogates of dialysis patients. One important finding is that many surrogates in this sample were experiencing meaningful levels of anxiety (Table 2; $n = 42$), some were experiencing depression symptoms ($n = 14$), and a few ($n = 7$) reported PTSS symptoms. Despite these rates of psychological symptoms, we found no association between these psychological variables and end-of-life decision-making confidence.

The lack of association between depressive symptoms and decision-making confidence is noteworthy in light of literature on "depressive realism" (Alloy & Abramson, 1988; Dobson & Franche, 1989). This literature suggests a somewhat counterintuitive relationship between psychological status and decision-making confidence. Specifically, persons with more depressive symptoms may be more realistic/accurate about their decision-making abilities, and thus less confident, compared to their less depressed counterparts. Alternatively, it has been shown that depressive symptomatology is associated with difficulty in making decisions; that is to say, an inability to decide one way versus another (Clark, vonAmmon Cavanaugh, & Gibbons, 1983; Koo, et al., 2005). The current body of evidence, including our study findings, does not suggest a consistent relationship between psychological symptoms and one's own confidence in acting as a surrogate decision maker.

Table 1. *Sample Characteristics*

Variable	**African American (*n* = 79)**	**Caucasian (*n* = 41)**	**Total sample (*N* = 120)**
Surrogate			
Age, *M* ± (*SD*)	51.96 ± 13.72	56.95 ± 14.47	53.67 ± 14.12
Female, *n* (%)	51 (64.6)	32 (78.0)	83 (69.2)
Relationship to patient			
Spouse or partner	31 (39.2)	22 (53.7)	53 (44.2)
Parent	3 (3.8)	3 (7.3)	6 (5.0)
Sibling	12 (15.2)	1 (2.4)	13 (10.8)
Child	26 (32.9)	12 (29.3)	38 (31.7)
Friend	3 (3.8)	3 (7.3)	6 (5.0)
Other relative	4 (5.1)	0	4 (3.3)
Years of formal education	13.41 ± 2.27	13.73 ± 2.42	13.52 ± 2.32
Married	45 (57.0)	30 (73.2)	74 (61.7)
Currently employed full time	36 (45.6)	13 (31.7)	49 (40.8)
Total annual household income			
< $13,000	15 (19.0)	7 (17.1)	22 (18.3)
$13,000 – $29,999	25 (31.6)	10 (24.4)	35 (29.2)
$30,000 – $49,000	16 (20.3)	11 (26.8)	27 (22.5)
> $49,000	19 (24.1)	11 (26.8)	30 (25.0)
Refused to answer	4 (5.0)	2 (4.9)	6 (5.0)
Currently live with patient, *n* (%)	47 (59.5)	28 (68.3)	75 (62.5)
Religion, Protestant	69 (87.3)	33 (80.5)	102 (85.0)
Importance of spirituality or religious belief in life:			
Very important – Extremely important	75 (94.9)*	28 (68.3)	103 (85.8)
Have lost a close family or friend	76 (96.2)	37 (90.2)	113 (94.2)
Involved in tough medical decisions for the family or friend	26 (32.9)	9 (22.0)	35 (29.2)
Quality of relationship with patient (1 – 5), *M* ± (*SD*)	4.41 ± 0.78	4.38 ± 0.71	4.39 ± 0.75

$*p < 0.001$

Table 2. *Mean Scores of Symptoms of Anxiety, Depression, and PTSS*

	African American (*n* = 79)	**Caucasian (*n* = 41)**	**Total sample (*N* = 120)**
Anxiety, *M* ± (*SD*)	5.84 ± 3.81	6.41 ± 3.45	6.03 ± 3.69
≥ 8, *n* (%)	30 (31.7%)	12 (29.2%)	42 (35.0%)
Depression	3.53 ± 2.79	4.44 ± 2.93	3.84 ± 2.86
≥ 8	7 (17.1%)	7 (8.9%)	14 (11.67%)
PTSS	18.81 ± 10.14	20.24 ± 8.56	19.30 ± 9.61
> 35	3 (3.8%)	4 (9.8%)	7 (5.8%)

Table 3. *Mean Scores of Surrogate Decision-Making Confidence by Item and Overall Sample*

Item	**African American (*n* = 79)**	**Caucasian (*n* = 41)**	**Total sample (*N* = 120)**
I feel confident that…			
1. I understand what my loved one's preferences are	3.40 ± 0.88	3.58 ± 0.72	3.46 ± 0.83
2. I can make a decision for my loved one as to what treatment he/she should have, even in a highly stressful situation	3.40 ± 0.90	3.34 ± 0.71	3.38 ± 0.83
3. I can ask questions to get the facts about the benefits or risks of each medical choice without feeling discouraged	3.74 ± 0.59	3.79 ± 0.41	3.75 ± 0.53
4. I can handle unwanted pressure from others, such as other family members or health care providers, in making decisions for my loved one	3.35 ± 1.03	3.37 ± 0.71	3.36 ± 0.93
5. I can communicate with doctors and nurses about my loved one's wishes	3.78 ± 0.62	3.66 ± 0.75	3.74 ± 0.67
Total score	17.66 ± 3.15	17.76 ± 2.38	17.70 ± 2.88

Table 4. *Associations Between Sociodemographic Variables, Psychological Symptoms, and*

Similar to findings in studies by Nolan et al. (2009) and Song, Ward, and Lin (2012), surrogates in this study were highly optimistic about their ability to make end-of-life decisions for their loved ones. We found that this confidence was significantly related to their perceived quality of relationship with their loved ones. In the study by Song et al. (2012), surrogates' confidence was not based on the actual understanding of their loved one's end-of-life care preferences and surrogate decision-maker roles they would need to play during the end-of-life stage. In other words, surrogates who perceive a good relationship with their loved ones may be overly confident about end-of-life decision making. Further studies are needed to examine the role of decision-making confidence in actual end-of-life decision making, and the psychological outcomes afterward.

We did not find an association between surrogates' psychological symptoms and whether or not they had been previously involved in end-of-life decision-making for their loved ones. However, we recognize that the way we had operationalized "previous end-of-life decision-making experiences" was likely insufficient to identify its relationship with surrogates' current psychological symptoms as we did not include questions to assess their experiences in depth. In addition to the limited operationalization of previous end-of-life decision-making experiences, another study limitation was that decision-making confidence was skewed toward the positive, high end of the scale, and had limited variability. These features of the variable's distribution may have limited its association with other study variables. Most critically, this was a descriptive, correlational study that sets the stage for but does not accomplish the need to examine linkages between surrogates' psychological variables before and after experiencing the challenge of engaging in end of life decision making for a loved one.

In summary, we did not find the associations between surrogates' psychological symptoms and end-of-life decision making confidence. Surrogates' decision-making confidence was high in general and significantly associated with their perceived quality of relationship with their loved ones (dialysis patients). There were no racial/ethnic differences found in these relationships. Because of our study limitations described above, the lack of relationships between psychological symptoms and end-of-life decision-making confidence warrants further research. Nonetheless, our finding of surrogates' overconfidence in end-of-life decision making that may be based on their perceived relationship quality suggests that significant efforts are needed to help surrogate decision-makers realize that they might not be fully aware of their loved ones' wishes or how they would handle such a stressful situation. The clinical implication of this finding is to consider, in addition to the current emphasis on clarifying and documenting patents' wishes in advance care planning, to include of better preparation of the surrogates.

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