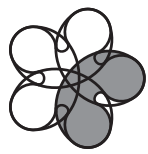


# The Journal of Nephrology Social Work



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## THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of nearly 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.

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## JOIN THE *JNSW* EDITORIAL BOARD

*The Journal of Nephrology Social Work* is always interested in attracting CNSW members who will serve as Editorial Board members to help with the planning, solicitation, and review of articles for publication.

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### CALL FOR MANUSCRIPTS

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
- Kidney Transplant
- Pediatric Issues
- End-of-Life Concerns
- Sleep Disorders
- Sexual Functioning
- Aging and Gerontological Issues
- Disaster Preparedness
- Comorbid Illnesses
- Home Dialysis Modalities
- Professional Roles
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## 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, methods, results, and discussion of original research. Length usually should not exceed 15 double-spaced pages, including references.

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

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

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

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

### MANUSCRIPT SUBMISSION

**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.

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**Tables.** All tables should be double-spaced and each should begin on a separate page. Tables are numbered sequentially according to the order in which they are first mentioned in the manuscript (*Table 1*, *Table 2*, etc.) and are given an appropriate title that is centered at the top of the page. Table Notes should be a single, double-spaced paragraph, set after the last line of data. The first line should be flush and begin with the word *Note*. Please submit all table files in black and white (grayscale), high resolution format.

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).

#### 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.
- Most other file formats (PowerPoint, JPG, GIF, etc.) are not of sufficient resolution to be used in print. The resolution for all art must be at least 300 dpi. A hard copy of each figure should accompany the files. These images should be black and white (grayscale) only. They should be TIFF or EPS file formats only.
- In addition to the images that appear in your word processing file, it is important to send the images as individual files too. These images should be black and white (grayscale) only. They should be TIFF or EPS file formats only.

## The Impact of Psychosocial Factors on Peritonitis: A Social Work Approach

Shelly D. Crumley, MSW, LCSW, DaVita Med Center @ Home, DaVita Med Center Peritoneal Dialysis, DaVita Binz PD/HHD Home Training Program, Houston, TX

*Peritonitis is a preventable infection in people on peritoneal dialysis (PD). Psychosocial factors that may impact the onset of peritonitis include complacency, depression, forgetfulness, expediency, caregiver stress/burnout, and the "pet factor." The clinical social worker is skilled in addressing each of these areas to reduce the rate of peritonitis in the PD population. Intervention methodology, such as motivational interviewing, depression assessment, behavioral therapy, the dispelling of myths, stress reduction, adjustment counseling, and pet relationship significance assessment are utilized to effectively address peritonitis prevention. Patient education on psychosocial factors that may lead to peritonitis followed by appropriate social work clinical interventions may be implemented for a true interdisciplinary approach to peritonitis prevention.*

#### INTRODUCTION

Peritonitis ... The word invokes concern, even fear, in those on peritoneal dialysis (PD). Peritonitis is an infection of the peritoneum that results from bacteria entering the catheter tubing and into the peritoneal cavity (Shapiro, 2004). Other causal factors include: "bacteria from an exit site infection, bacteria already in the stomach or intestinal tract (due to diverticulitis or appendicitis), and touch contamination (The open end of the PD catheter or transfer set touches a non-sterile object, such as a hand or bed sheets; system accidentally disconnects; or a tear develops in the catheter or transfer set.)" (Shapiro, 2004).

People on PD are trained extensively in techniques for preventing such infections and educated about the consequences of peritonitis, such as increased medication, illness, and pain. A severe case of peritonitis may result in hospitalization, removal of the PD catheter, or, most tragically, death. Peritonitis caused by inadequate infection control practices is preventable. Infection control techniques include appropriate methods for hand washing and use of mask, proper connection/disconnection techniques with the transfer set, and meticulous catheter care (Shapiro, 2004).

If peritonitis is preventable, why do so many people get it? The 2011 Dialysis Facility Report indicates an average of 24 out of every 100 Medicare-eligible people on PD in the United States had a diagnosis of peritonitis in 2010 (Centers for Medicare & Medicaid Services, University of Michigan Kidney Epidemiology and Cost Center, & Arbor Research Collaborative for Health, 2011). While most education available regarding the topic of peritonitis deals with prevention and treatment, little has been written on the possible emotional and/or psychosocial factors that may contribute to an individual's peritonitis infection. This paper explores the psychosocial elements that may impact the onset of peritonitis, including complacency, depression, forgetfulness, expediency, caregiver stress/burnout, and the "pet factor." This paper also explores social work theories that could be the foundation for interventions that the clinical social worker may perform to address each element and assist in the reduction of peritonitis rates in this population.

#### PSYCHOSOCIAL FACTORS IMPACTING PERITONITIS

##### Complacency

Complacency is characterized in this paper with the mindset: "It won't hurt if I skip that step ... I can get away with it." Complacency is defined as the failure to see the seriousness of a situation or to follow good procedure or attention to detail (Dekker, 2002). Long-term treatment of chronic illness can result in adherence fatigue, impacting successful medical management of the illness. A study by the National Institutes of Health, the Agency for Healthcare Research and Quality, and the Department of Veterans Affairs found that, as treatment progressed, participation in treatment adherence declined. According to Dr. Vincent Lo Re, this is consistent with behaviors for other chronic conditions in which "pill fatigue" is often presented (as cited in Auer, 2011). It is this author's opinion that complacency acts as an erosive device, undermining the foundation of sound infection control practices necessary for successful PD, and is the primary psychosocial factor that leads to peritonitis in people on PD. Complacency may occur as a result of a false sense of security, weariness, fatigue, or boredom. A quality improvement program conducted by Alcaraz, Brzostowicz, and Moran (2008) found that the main cause of peritonitis was related to a breakdown of adherence to proper infection control techniques. People began creating their own variation of proper procedures as early as 1 month following the completion of PD training, and exhibited increased complacency behaviors after 2 to 3 years without peritonitis events (Alcaraz et al., 2008). Menon notes that complacency and lackadaisical behaviors may present themselves when a person develops a false sense of security from absence of problems over a period of time (2005).

Weariness is a common denominator for both fatigue and boredom. Fatigue is defined as "a condition characterized by a lessened capacity for work and reduced efficiency of accomplishment, usually accompanied by a feeling of weariness and tiredness." Fatigue can have a sudden onset or be chronic and endured over a period of time (Fatigue, 2004). Boredom is defined as "the state of being weary and restless through lack of interest" (boredom, n.d., para. 1).



Nonadherence to infection control practices may be a result of boredom as well as weariness from performing daily/nightly PD treatments. Juan Olivero, Sr., MD, medical director of the DaVita Binz PD/HHD Training Program compares a person on PD following infection control practices with a pilot needing to follow flight safety procedures. Each time a pilot prepares for flight, he completes a flight safety procedure. Even if the pilot finds this process boring, monotonous, irritating, or time consuming, it is an essential element in ensuring the safety of the flight. Skipping even one step in the flight safety procedure can lead to flight complications, some possibly tragic. Likewise, it is important for people on PD to follow proper infection control practices with each connection/disconnection (personal communication, June 24, 2011). Glazer, Laurel, and Narasimham (2007, p. 206) note a possible link between a decreased sense of safety awareness over time and a lack of concern in airline employees in following safe operation practices.

Similarly, weariness and boredom associated with participating in daily/nightly PD therapy may also create desensitization in people on PD to the risks of not following safety practices. When exploring the correlation between fatigue and workplace errors for the health care professional, Dowson and Zee (as cited in Ellis, 2008) indicated that the effects of fatigue in the medical setting have been shown to negatively impact the health care worker's "alertness, vigilance, concentration, judgment, mood, and performance." Likewise, errors made by pharmacists have included fatigue associated with high prescription volume and overwork, as well as boredom during slower periods and lack of attention (Glanutsos, 2008).

To address complacency, the person must first be educated regarding infection prevention techniques and consequences of nonadherence to such infection control practices. He or she receives extensive education by the training nurse on these issues during the PD training program. Once education has been provided, the clinical social worker joins in collaboration with the interdisciplinary team to keep the person on track with safe practices. The clinical social worker works in partnership with the person through motivational interviewing (MI) to identify personal issues related to complying (or not complying) with infection prevention practices (McCarley, 2009). MI consists of four essential components: 1) expressing empathy, 2) rolling with resistance, 3) developing discrepancies, and 4) supporting self-efficacy (MINT, William R. Miller, & Stephen Rollnick, 2003).

Through empathy, the clinical social worker builds rapport and sees the struggles with safe practice issues through the eyes and experiences of the individual, thereby gaining an understanding from the person's point of view (Welch, Rose, & Ernst, 2006). Next, the clinical social worker avoids power struggles by "rolling" with the individual's resistance to change. Rapport is strengthened when the

clinical social worker resists challenging or arguing with the person in an attempt to force him or her into compliance (MINT, William R. Miller, & Stephen Rollnick, 2003). Through effective listening, the clinical social worker helps the person to become aware of contrasting behaviors versus the person's own identified goals in the "developing discrepancy" phase (Welch et al., 2006). Lastly, the clinical social worker provides ongoing empowerment and patient-identified problem-solving encouragement through the "support of self-efficacy" phase. The clinical social worker brings to light the person's previous achievements and his/her own internal power strengths to inspire hope about making changes for the person's well-being (MINT, William R. Miller, & Stephen Rollnick, 2003).

The clinical social worker assesses the weariness level of a person on PD to detect possible unknowing or subconscious ceasing of sound practices in order to return to in-center hemodialysis. If identified, the clinical social worker explores with the person, confirming his or her modality desires; collaborates with the interdisciplinary team for possible PD treatment modifications; and assists with physician-directed modality change as warranted.

#### Depression

Weariness and boredom may be a natural result of long-term participation in PD therapy and may or may not be related to depression. Depression is characterized in this paper with the mind-set: "I don't care. It just doesn't matter if I get peritonitis." Decision making on whether to follow peritonitis prevention practices may be impacted by depression. Depressive symptoms range from mild to severe. Symptoms of depression may include changes in appetite, insomnia or hypersomnia, fatigue, low self-esteem, impaired concentration, feelings of hopelessness, recurrent thoughts of death, or suicidology (American Psychiatric Association, 1995). Care must be taken for a collaborative approach with the physician in ruling out physical symptoms related to depression. Once depression has been diagnosed, each symptom may affect a willingness to participate fully with infection control practices.

The clinical social worker provides depression assessment for a person on PD by exploring the prevalence of depressive symptoms in the person's life. The clinical social worker may utilize various tools for assessing depression, including the Kidney Disease Quality of Life-36 survey (RAND & University of Arizona, 2000) and the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Once symptoms of depression are identified, the clinical social worker explores possible causal agents that lead to depression. Methods of depression treatment are based on the causal agents identified and may include clinical theory applications, problem-solving techniques, identification and reinforcement of effective coping mechanisms, discussion with the individual and his or her nephrologist regarding psychopharmaceutical intervention, assessment for harm to self or others, and

referral to community mental health/psychiatric services. The National Association of Social Workers' professional code of ethics charges the social worker with the responsibility of assessing for possible suicidology, whether conscious or subconscious, through the means of peritonitis (2008). If suicidology is ruled out, then appropriate collaboration with the nephrologist and interdisciplinary team is required and intervention is made.

#### Forgetfulness

Another psychosocial factor that may be related to peritonitis is forgetfulness. Forgetfulness is characterized in this paper with the mind-set: "There's too much to remember. I can't keep it all straight." Many factors may affect an individual's memory.

Interventions for forgetfulness are presented in a dual approach. The clinical social worker may first assist the person in identifying a potential cause of the forgetfulness. Possible factors that may impact memory impairment include drug or alcohol usage, stress, depression, medication, adjustment issues, organic memory impairment, head injury, certain medical treatments, nutritional deficiencies, aging, and other medical issues (Hoch, 2010). Working in collaboration, the clinical social worker and the interdisciplinary team can help to identify the factor(s) impacting forgetfulness and work toward an appropriate intervention. Physician involvement is required in addressing possible medication or organic/medical factors. By addressing the causal factors of forgetfulness, the clinical social worker can work to reduce or eliminate the elements of stress, depression, or adjustment issues associated with forgetfulness.

The second approach to addressing forgetfulness is to employ behavioral therapy techniques via memory enhancers. People on PD are supplied with written instructions to use as guides during the training process. Guides such as the *Patient At-Home Guide* and *PD Procedure Guide* provide memory aids that are readily accessible to people on PD (Baxter Healthcare Corporation, 2009a, 2009b). The clinical social worker facilitates the adherence process by ensuring that guideline materials are presented on a level understandable to the individual.

The person on PD is then referred back to the written guidelines whenever forgetfulness is evident. Identification of any barriers to the utilization of the written instructions is to be discussed collaboratively with the PD nurse for an individualized memory-enhancing approach that also meets proper peritonitis prevention techniques. Increased caregiver support may also be initiated to address the element of forgetfulness.

#### Expediency

Expediency is characterized in this paper with the mind-set: "I don't have time for this. I need to speed up the process." Life is busy. Individuals on PD are not exempt from the

stresses of everyday life, which require effective time management. Nonadherence to peritonitis prevention techniques may actually increase the time related to PD, rather than lead to the desired goal of decreased time.

Expediency is best addressed by utilizing a two-step treatment method. The first step involves the person and interdisciplinary team exploring logistical issues related to timely implementation of each PD exchange. Which PD modality best serves the individual's needs: continuous ambulatory PD (CAPD) or continuous cyclical PD (CCPD)? For someone who leads a very busy daily schedule, incorporating three to four manual exchanges daily may lead to a temptation to skip infection control techniques in order to speed up the process. Such a person may be more suited to CCPD therapy, thereby freeing up his or her daytime hours, offering flexibility for a busy schedule, and reducing opportunities for contamination. Contamination risk is higher with CAPD due to the multiple connections needed to perform daily exchanges. For this reason, people on PD are frequently evaluated to go directly on CCPD, thereby reducing contamination risks.

The second step in addressing the issue of expediency involves patient education regarding the consequences of increased time needed to treat peritonitis. Nonadherence with peritonitis prevention techniques may lead to contamination of the PD catheter. Contamination of the PD catheter may lead to peritonitis. Once diagnosed with peritonitis, a person on PD must meet with the PD nurse for frequent visits until symptoms show improvement. Daily antibiotic therapy is the usual course of treatment for the next 2 to 3 weeks. The person undergoes additional infection prevention training with the PD nurse. A home visit from the PD nurse is also conducted. A more acute peritonitis may require hospitalization and possible abstraction of the PD catheter. Removal of the PD catheter requires a modality change to hemodialysis until the catheter can be reinserted and the person can return to PD (Shapiro, 2004).

Dispelling the myth that nonadherence to peritonitis prevention techniques will save time is an important element in addressing the issue of expediency. The clinical social worker works collaboratively with the person and the interdisciplinary team to ensure that patient education is presented on a level appropriate to the individual's understanding. The social worker then follows up with ongoing MI to address the element of expediency.

#### Caregiver Stress/Burnout

Caregiver stress/burnout is characterized in this paper with the mind-set: "I can't keep this up. This is more than what I bargained for." PD affects the family unit, not just the person who is sick. PD care partners must deal with their own issues of loss and change when partnering to care for people on PD. The decision to become a care partner in PD may be loaded; one made as a result of love and commitment, guilt and obligation, or a blend of these as well as

other motivations. Caregivers must find effective ways to deal with their own loss of freedom, aspects related to role change, increased stress, and communication issues within the partner relationship.

Although the main focus of treatment is centered on the PD patient, the Centers for Medicare & Medicaid Services have given a directive that "The social worker is expected to assist patients in achieving their psychosocial goals. Counseling services to patient and their families should be directed at helping the patient and family to cope with kidney failure and dialysis, follow the treatment plan, and achieve the patient's goals for rehabilitation" (2008).

The clinical social worker provides therapeutic intervention to the caregiver on topics such as adjustment and loss, stress identification and reduction, systems theory, relaxation techniques, support networks, successful communication, and reinforcement of effective coping skills. The social worker takes care to encourage self-care for the caregiver as well as enhanced communication techniques to help the patient and caregiver to understand each other's points of view.

#### The "Pet Factor"

The "pet factor" is characterized in this paper with the mindset: "My pets are my family. I want to have them around me." Pets are indeed members of the family. However, steps may be needed to prevent them from being a deterrent to safe PD. An individual who is comforted by sleeping with their dog or cat each night may need to consider daily manual exchanges rather than nightly cyclical treatments in order to facilitate reduced infection risk. Although this may seem to be common sense to most people on PD and their interdisciplinary team, the "pet factor" cannot be overlooked. Someone who resides alone may value the comfort of their pet more than the importance of sound infection control practices.

While most documentation available today cites the positive relationship between pet ownership and the improved health of the owner, very little is written citing harmful implications between pet ownership and compromised health of the owner. According to Dan Gibbons, executive director of the Chicago Anti-Hunger Federation, some pet owners who are poor value their pet companionship to the point of choosing to feed their pets instead of feeding themselves (as cited in Trice, 2011).

The clinical social worker addresses the "pet factor" by exploring the relationship significance between the person and the pet. Implementation of the appropriate PD modality (CAPD versus CCPD) is first examined, followed by ongoing education and monitoring of safe infection control practices. The clinical social worker provides empathy and effective listening while reinforcing sound infection control practices with the person on PD. For those whose pet companionship compromises adherence to sound infection control practices, interdisciplinary reassessment of PD candidacy must be considered. The clinical social worker

assists the person with physician-directed modality change to an alternate dialysis modality best fitting the person's needs, if warranted.

#### CONCLUSION

The key to correcting and changing a behavior is problem identification followed by behavior modification. The clinical social worker may take an active role in the prevention of peritonitis by providing education to the person on PD on psychosocial factors that may lead to peritonitis. PD programs have traditionally focused on the clinical skills of the nurse for addressing prevention and treatment of peritonitis. The time has come for the clinical social worker to impart education and therapeutic interventions in providing a true interdisciplinary approach to the prevention of peritonitis.

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## A Single-Participant Qualitative Case Study: Holism, Healing, and Health-Related Quality of Life in Hemodialysis— Reflections of a Long-Term Survivor

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*The author, a 28-year survivor of hemodialysis treatments, tells a story of his longevity through some of the precepts of holism. These include emphasizing individual growth and change, healing the whole person, and the role that individuals play in self-healing. The author recounts the roles that social, cultural, religious, and educational institutions played in his healing and his transformation from someone devastated emotionally, physically, and spiritually at first, into someone who feels more complete and vigorous at present. The author also derives practice, policy, and research implications from this narrative, for nephrology social workers helping patients to heal and live full lives.*

### INTRODUCTION

I had my first hemodialysis treatment on September 10, 1983, and have been receiving hemodialysis treatments since, with the exception of a 6-month hiatus due to a failed transplant. I was diagnosed with end-stage renal disease due to complications from polycystic kidney disease, and since that time, my life's journey has taken innumerable twists and turns. Surviving all of those challenges from being a hemodialysis patient has been both difficult and joyful. In reflecting on my life, I can view my longevity through the lens of holism. Thus, the focus of this essay is to examine how the concepts of holism have helped me survive and enhance my quality of life.

Holism is a concept that is central to health-related quality of life (Brown, Renwick, & Nagler, 1996). The term "holism" derives from the Greek word "holos" or "whole." It is defined as systems or organisms that are greater than and different from the sum of their parts (Hemphill-Pearson & Hunter, 1997; Baum, 2010), and explains nature's tendency to generate wholes from an aggregation of single, solitary parts (Baum, 2010). The concept, applied to health, focuses on the balance and interconnectedness of physical, social, psychological, and spiritual aspects (Levin, 2009; Patterson, 1998). Consequently, the main principle in holism is wholeness, or the unity and oneness of mind, body, and spirit. Therefore, in holism, all aspects influence each other while working in concert (Davis-Floyd & St. John, 1998; Hemphill-Pearson & Hunter, 1997; Levin, 2009; Mattson, 1982; Thornton & Gold, 1999).

This concept of holism is quite different from the mechanistic/technocratic model of health and medicine (Brouse, 1992; Davis-Floyd & St. John, 1998; Levin, 2009). In the mechanistic/technocratic model, there is a distinct segmentation and separation among mind, body, and spirit (Davis-Floyd & St. John, 1998; Levin, 2009; Mattson, 1982; Thornton & Gold, 1999). However, the concept of holism focuses on individual growth and change (Brouse, 1992; Patterson, 1998); healing the whole person with balance among the physical, social, emotional, and spiritual selves (Brouse, 1992; Checkland et al., 2008; Davis-Floyd & St.

John, 1998; Hemphill-Pearson & Hunter, 1997; Mattson, 1982; Patterson, 1998; Thornton & Gold, 1999, Thorpe, 2008); and also emphasizes the role that individuals, as opposed to health care providers, play in healing themselves (Davis-Floyd & St. John, 1998; Epstein, Senzon, & Lemberger, 2009; Jobst, Shostak, & Whitehouse, 1999; Mattson, 1982; Thornton & Gold, 1999).

### INDIVIDUAL GROWTH AND CHANGE

When faced with renal failure that September of 1983, I was not concerned with individual growth and change. This became an especially challenging time of my life. Anger, depression, and sadness were the predominant emotions that I experienced at the time, due to the realization that I would have to rely on hemodialysis in order to live. To say the least, my spirit was broken. To compound these feelings, I lost my father, my job and my apartment, and my same-gender partner and I separated, all within a year of being diagnosed with kidney failure. It seemed that life could not get any worse.

However, I gradually began to recover from this trauma as I began doing volunteer counseling at a local city agency. This part-time volunteer work actually gave me a sense of purpose, and was the springboard to greater employment opportunities. My small family was supportive of my efforts without being overbearing, and I was beginning to be embraced by a nucleus of fictive "kin" (network of friends) who were concerned about my well-being. At this time, social support was crucial in my quest to survive and have a relatively good quality of life (Kimmel, Emont, Newmann, Danko, & Moss, 2003; Patel, Shah, Peterson, & Kimmel, 2002).

Additionally, I was also deeply involved with my religious institution at this particular time. Seminal research by Hill (1971, 2003) posits that religion and kinship networks have helped African-Americans cope with a myriad of deleterious situations in society. Park (2005, 2007) and Pargament (1997) posit that religion can help individuals find comfort, solace, peace, and strength in the face of health crises. Thus, my involvement in the religious institution, to a certain degree, helped me cope with my renal failure.

However, there were two pivotal moments in this journey that fostered tremendous individual growth and change. First, I left the religious institution that was my denomination from birth because the minister's teachings on sexual identity were causing me great distress. This led me to a more progressive religious institution where I was accepted, enabling me to grow spiritually.

Second, I was given the opportunity to study doctoral-level social work. Daniels (2001) and Williams (2008) both believe that, in order for an individual with a chronic illness to thrive, life-enhancing opportunities must be made available to them. As an African-American gay male with a chronic illness, I lived with society's bigotry toward vulnerable and marginalized groups. Pursuing my doctoral degree boosted my confidence, self-esteem, and sense of purpose. After 8 years of intense study and a couple of health-related setbacks, I received my PhD in 2003. I have subsequently taught full-time at two universities in their departments of social work, while still undergoing thrice-weekly hemodialysis.

### HEALING THE WHOLE PERSON

Healing the whole person is a hallmark of holistic health and has been central to my longevity on hemodialysis. This concept involves striking a balance among the various aspects of human existence (Checkland et al., 2008; Thorpe, 2008). There has to be harmony among physical, social, emotional, and spiritual realms. I gave equal attention to all of those entities. Although I try to keep myself physically well by engaging in health-promoting activities, such as exercise, eating nutritious meals (within the confines of the renal diet), and refraining from injurious lifestyle actions, I also try to surround myself with persons who have positive attitudes. Additionally, I try to enjoy myself at various social and cultural events, including concerts, plays, and parties. These events lift my spirits. Some of these events also have spiritual dimensions, fostering connectedness to others (Park, 2005, 2007). Being around positive, life-affirming persons, while enjoying social and cultural events, helps me maintain a more harmonious emotional state. Physical, social, and emotional care have played equal parts in helping to improve my health-related quality of life, with no part overshadowing the other.

For me, healing the whole person also involved affirmation of my sexual orientation. My life as an African-American gay man was fraught with anxiety at times. Even though I had come out as a gay man in the early 1970s, being diagnosed with kidney failure in 1983 added another challenge to my existence. Egan and Kadushan (2007) speak about the multiple layers of oppression African-American lesbian, gay, bisexual, and transgender individuals face. In order to counteract those negative influences, I had to pursue life-affirming strategies to enhance my quality of life. These strategies included reading gay and African-American literature, attending African-American and gay pride events,

and becoming a member of a gay-affirming religious institution, which also had a history of supporting equal rights for African Americans and other persons of color. This certainly gave me a more positive sense of self, and helped restore a sense of wellness to my whole being.

### HEAL THYSELF

As for the role individuals play in helping to heal themselves, Epstein, Senzon, and Lemberger (2009) identify a healing paradigm that they term "reorganizational healing." In this model, they propose that disease can be viewed as an impetus for growth, enhanced awareness and, ultimately, an opportunity to become "stronger, healthier and wiser" (p. 475). Certainly, confronting the vicissitudes of hemodialysis for the past 28 years has helped me to become emotionally stronger, and perhaps wiser. Through these years, I may have declined physically somewhat, but I do feel stronger emotionally. Having to deal with venipunctures 3 times a week, sitting for treatments 3.5 to 4 hours at each session, and disciplining myself to a renal diet have given me an emotional toughness that I did not possess before.

Additionally, Jobst, Shostak, and Whitehouse (1999) aver that individuals can bring different perspectives to illness that totally reconfigure the patient/health care worker relationship. Over the years, I have developed an equal relationship to my health care workers. I view them as equals, rather than "superior" health care professionals. I feel that my knowledge of what it takes to live well as a dialysis patient is just as important as their technical expertise. I also emphasize to my health care providers that I am the most important person in the relationship. I assert my rights in the decision-making process. Initially, this may cause some strain in the relationship, but when providers see that I am serious about taking care of my health, they usually assent.

### IMPLICATIONS FOR NEPHROLOGY SOCIAL WORKERS

In this narrative, I have attempted to illuminate how certain concepts embedded in holism have informed my journey as a hemodialysis patient. Specific narratives and life stories cannot be used to generalize beyond each situation (Neuman, 2009). However, I believe that my story does have broader implications for those in nephrology practice. Certainly, holism constructs would not seem to be foreign to nephrology social workers. Most social workers are trained to embrace theoretical constructs, such as the ecological, social systems, and strengths perspectives. The conceptual foundation of these theories and constructs certainly dovetails with holism (Dominelli, 2002; Ungar, 2002).

In order to use holism in the dialysis unit, nephrology social workers should be adept at urging dialysis patients to become more vocal about their own care. This means that social workers will have to become cognizant of and divest themselves of any paternalistic feelings they may have about their patients. They, and the other health care



providers in the dialysis unit, must begin to view dialysis patients as partners in the health care delivery system who, together, can make effective decisions about their own care (Johnson, Slusar, Chaatre, & Johnsen, 2006; Ungar, 2002). Thus, nephrology social workers should view dialysis patients as partners in the decision-making process, not as clients with little or no control over their situation. This would help to engender a sense of empowerment that would help dialysis patients navigate this complex health care process with a sense of self-determination.

In order for nephrology social workers to begin to see dialysis patients as partners, they must also be culturally sensitive and culturally competent (Spector, 2009). They must realize that all patients, regardless of their education, race, gender, sexual orientation, disability, and socioeconomic status, bring some strengths to the situation. This means going beyond the usual required online course modules. Nephrology social workers, in order to work skillfully and effectively with patients of different backgrounds, may have to leave their comfort zones and learn about other races and cultures through personal experiences, respectful curiosity, and self-education. Most of the social workers whom I have encountered in my 28 years on dialysis have been white females. For the most part, they were compassionate, caring, and understanding. However, I did encounter one who was seemingly not that empathic and appeared to be insensitive to the plight of African-American men and the challenges they face. This social worker seemed so indifferent to the plight of African Americans on dialysis that she neglected to cover the evening shift, which was composed of many African-American men. Subsequently, the patients complained to the Renal Network and she did begin to see the evening shift patients, although seemingly reluctantly. Consequently, when African-American men constitute the largest racial and gender group receiving hemodialysis (United States Renal Data System, 2009), one has to ask what can the profession do to encourage more African-American males and other people of color to join the field?

Also, for patients to live well and holistically on hemodialysis, nephrology social workers must ask patients questions regarding the overall meaning of hemodialysis in their lives. The Kidney Disease Quality of Life (KDQOL) survey helps social workers ask patients about the changes they would make to improve their lives. It not only involves social workers asking about patients' social situations, but also how their physical and spiritual lives connect with the other parts of their beings. Social workers also determine from patients whether they want to live healthier and more enjoyable lives, and what it would take, from the patients' perspectives, to achieve that goal. Furthermore, nephrology social workers ascertain from patients the extent to which they wish to be involved in and participate in their own treatment decisions. Regarding implications for policy from my narrative, Epstein et al. (2009) and Williams (2008) assert that opportunities and resources must be made available to individuals with chronic health conditions in order for them to live full

lives. These include educational and training opportunities, safe and affordable housing, and access to preventive health services.

Additionally, Epstein et al. (2009) assert that these individuals must also be resourceful in seeking out the best courses of action for their well-being. Admittedly, I may have had an advantage in this regard as opposed to many other hemodialysis patients.

When diagnosed with kidney failure in 1983, I already had my master's of social work degree, having obtained it in 1975. Because of my educational background in social work, I may have also had more insight into how to navigate the resource network in order to sustain myself. Relative to opportunities, I was given the chance to teach as an adjunct professor in a school of social work, to work as a research assistant in a university-sponsored research project, and to supervise research assistants in a medical school research project. However, my greatest opportunity came when I was admitted to a doctoral program in a school of social work. Matriculation in a doctoral program in social work had been a goal since I had begun teaching as an adjunct professor in social work. However, it had seemed unattainable since I was on hemodialysis. Fortunately, I came to realize that placing limitations on my aspirations was self-defeating. Overcoming limitations was what ultimately led me to become successful in my quest.

Thus, nephrology social workers and other practitioners involved in the care of people on hemodialysis should continue to advocate for more enlightened policies that will assist them in their pursuit of life-affirming activities. This means that social workers must continue to advocate for the rights of patients to pursue employment or educational undertakings without being penalized financially by governmental agencies trying to assist persons with disabilities (Tremblay, Smith, Porter, & Weathers, 2011). These authors assert that receiving Social Security Disability Insurance benefits for a period of time and then losing those benefits after a trial work period has ended is a powerful disincentive to work for many recipients. This may be especially pertinent for younger people on hemodialysis who have not yet established a solid employment history or who wish to begin or complete an educational endeavor.

This narrative falls within the vein of single-participant qualitative research. As such, I believe that more qualitative research studies should be performed with hemodialysis patients. Most studies I have read of hemodialysis patients are quantitative in nature and may not capture the full breadth and depth of the lived experiences of hemodialysis patients. There are many ways of knowing and the various fields of qualitative research also contribute to this knowledge base (Neuman, 2009). Stories and narratives of hemodialysis patients can be powerful documentation as to their strength and resiliency.

## CONCLUSION

In summary, I have attempted to tell my story through the lens of holism (Epstein et al., 2009). Through holism, I have intertwined the precepts of individual growth and change, healing the whole person, and the role individuals play in healing themselves. This has been my story; not all hemodialysis patients will make progress in the same way. Some have been too scarred emotionally and physically to recover from the devastating effects of end-stage renal disease, along with discrimination, lack of understanding, and other societal problems. However, there will be some with this illness who will want to live full and vibrant lives. It is with these patients that nephrology social workers will be most successful. I hope my story further enlightens and educates nephrology social workers and other professionals on how to assist patients who wish to live holistically while overcoming obstacles.

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## The Application of Acceptance and Commitment Therapy with Hemodialysis Treatment Adherence: A Case Study

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*Individuals diagnosed with end-stage renal disease (ESRD) who choose hemodialysis as their renal replacement therapy normally receive treatment 3 times a week in an outpatient facility. Adjusting to this life-sustaining treatment regimen involves creating a new way of life that challenges the patient's coping mechanisms. Adherence to the hemodialysis prescription is a major problem among people who have ESRD and significantly impacts their treatment outcomes and mortality rates. This study attempts to explore the use of acceptance and commitment therapy as a possible intervention for nonadherence to hemodialysis.*

### INTRODUCTION

Adherence to a life-sustaining renal replacement therapy prescription, such as hemodialysis, is a major issue among people with end-stage renal disease (ESRD). Nonadherence to the prescribed hemodialysis regimen is a common problem and is associated with increased morbidity and mortality (Denhaerynck, Dominique, Fabienne, Garzoni, Nolte, & De Geest, 2007). Patterns of nonadherence are typically established in the first 6 months of treatment and continue thereafter. Missing dialysis treatments increases a person's risk for infection, cardiovascular disorders, and hospitalization.

People with ESRD are required to permanently alter their lifestyles to accommodate the hemodialysis schedule. They experience a diminished sense of control and often seek methods to re-establish that control. These behaviors may manifest in positive or negative ways. A common theme in the adherence literature is the patient's desire to exert a measure of control over the disease and the dialysis process. Nonadherence may be one way that people on hemodialysis attempt to exert some control over their lives (Breiterman-White, 2004).

Barriers to treatment adherence may be due to concrete issues such as transportation or conflicting work/family schedules. However, nonadherence may also be a sign of emotional or psychological problems, such as depression. Depressive symptoms are present in approximately 30% of patients receiving chronic dialysis therapy, making it the most common psychiatric problem in these patients (Khalil, Lennie, & Frazier, 2010). Depressive symptoms may compromise an individual's ability to adhere to the hemodialysis regimen and instill hopelessness about the disease and prognosis. Decreased behavioral compliance with the dialysis prescription is correlated with an increased level of depressive affect in people on hemodialysis (Kimmel & Peterson, 2005).

Nephrology social workers are mandated by the Medicare Conditions for Coverage (Centers for Medicare & Medicaid Services, 2008) to be part of the interdisciplinary team in an outpatient dialysis unit. They provide a variety of concrete services and psychosocial interventions to this challenging population. Addressing the issue of nonadherence is relevant to the role of nephrology social work. Providing

skilled psychosocial interventions, such as acceptance and commitment therapy (ACT), might possibly ameliorate patient risk factors and treatment outcomes. People with ESRD are more likely to access these psychosocial treatment services through their nephrology social workers than anywhere else (Callahan, 1998).

### ACT

ACT (Hayes, Storsahl, & Wilson, 1999) is a modern behavior therapy that uses acceptance and mindfulness interventions in combination with commitment and behavior change strategies to help clients build more purposeful, meaningful lives (Flaxman, Blackledge, & Bond, 2011). Considered to be one of the "third wave" cognitive behavioral therapies, ACT has been gaining momentum in intervention research literature over the past decade (Montgomery, Kim, & Franklin, 2011).

ACT is theoretically rooted in relational frame theory (RFT), a behavioral theory of human language and cognition. RFT explains why sights, sounds, and events can trigger painful thoughts and emotions. RFT suggests that a more practical way of addressing problematic thoughts and emotions involves interventions that develop the ability to experience these emotions in a different manner, rather than attempting to change the emotions.

There is an existential component to the ACT model: providing an opportunity to find meaning and purpose in one's life, even in the midst of pain and suffering. According to Frankl (2006), the meaning in life and self-transcendence are essential for survival and healing. Doing what is consistent with our highest value discovers the meaning in life. In ACT, the goal is not just to reduce human suffering, but to help people grow as a result of their suffering and to use those experiences as a springboard to create rich and meaningful lives (Harris, 2009).

ACT's two major therapeutic goals are: 1) fostering acceptance of problematic thoughts and feelings that cannot be controlled and 2) commitment and action toward living a life according to one's chosen values. ACT does not attempt to have people alter their thoughts and feelings, but attempts to change their responses to thoughts and feelings. ACT therapists direct people toward becoming more

accepting of their emotions and present circumstances in the face of strong emotions they might otherwise be avoiding. They also assess how people struggle to resolve their problems and direct them to give up those struggles that might be making their problems worse (Montgomery, Kim, & Franklin, 2011).

ACT suggests that if psychological distress is a normal part of life that cannot be avoided, and if frequent avoidance tends to both exacerbate distress and decrease quality of life, then psychotherapy should help clients find ways to accept the distress that arises in the course of pursuing a meaningful, purposeful, and vital life (Flaxman, Blackledge, & Bond, 2011).

ACT consists of 6 therapeutic core processes that can be divided into 2 main components: mindfulness and acceptance processes, and commitment and behavior change strategies. Mindfulness and acceptance processes include: 1) acceptance: the willingness to experience any degree of psychological distress, and continue to move forward to experience what is valued; 2) cognitive defusion: techniques designed to alter the context in which one views thoughts, particularly thoughts that produce harm; and 3) self-as-context: a person's view of him- or herself, based on aspects of what one is currently thinking and feeling. These 3 processes help transform the cognitive and emotional barriers that appear to stand in the way of a values-driven life.

Commitment and behavior change strategies center around: 1) contact with the present moment: closely monitoring how one is effectively or ineffectively behaving in the present moment; 2) values: verbal statements about what an individual desires to experience throughout their lives; and 3) commitment: behaving consistently to work toward one's values.

These 6 core processes are linked to each other to enhance psychological flexibility. Fletcher and Hayes (2005) defined psychological flexibility as the ability to fully contact the present moment, to be mindful of the psychological reactions it produces, and to change behavior to enhance life, which is driven by fulfilling chosen values. Increased psychological health, from an ACT perspective, involves increased psychological flexibility.

There is no correct order when working on these 6 processes and not all require concentration. ACT therapists use a variety of tools and techniques for each process, such as metaphors, paradox, and experiential exercises.

Treatment using ACT begins with an assessment of one's experiential avoidance, the act of avoiding unpleasant thoughts, emotions, and other private experiences (Flaxman, Blackledge, & Bond, 2011). ACT targets experiential avoidance strategies (also known as emotional control strategies) only when clients use them to a degree that they become harmful. Some experientially avoidant behaviors, such as excessive drinking and drug use, cause

physical harm or compound the problem. Behaviors involving procrastination and avoidance of conflict make the precipitating distress worse.

ACT has been studied with a variety of illnesses that social workers are frequently called upon to help manage and treat in mental health and health settings. ACT has been proven effective with a diverse range of clinical conditions, such as depression, obsessive-compulsive disorder, workplace stress, chronic pain, the stress of terminal cancer, anxiety, post-traumatic stress disorder, anorexia, substance abuse, and even schizophrenia (Harris, 2006).

This study attempts to explore the application of ACT to address the problem of nonadherence with the dialysis prescription. The process of adjusting to and learning to live with ESRD is complex, involving strong reactions to the loss of life as it was and the re-establishment of a new identity. ACT's processes of clarifying values and committing to actions, which promote an increase in quality of life, may be beneficial to people with ESRD.

The goals of this case study are to determine if the application of ACT can be successful in increasing hemodialysis prescription adherence and can improve one's quality of life.

### CASE STUDY

#### *Psychosocial History*

Steven was a 49-year-old single Caucasian man who had congenital facial abnormalities. He was abandoned by his biological mother at birth and adopted by his present family at age 13, although they had been a part of his life from age 4. Steven was a high school graduate, had never married, and had been employed in the food service industry for most of his life.

Steven lived alone in a rented room and worked part-time in a supermarket deli. He had a history of drug and alcohol abuse, and had three inpatient rehabilitations, each of 3 months duration, between 1992 and 2000. Steven was incarcerated several times between ages 18 and 33 for assault and driving while intoxicated. Steven still drank occasionally and smoked marijuana.

Steven was highly independent and had supportive family and friends. He had suffered from two major losses in his life. Steven's adopted father was in an automobile accident, which left him comatose for 5 years. He died in 1992. Steven's fiancé died in 1996 from cystic fibrosis.

Steven stated he had abandonment and trust issues. However, once a trusting relationship was developed, Steven was very open with information and honest feelings. Steven displayed a friendly demeanor, but angered easily. He had a tendency to be critical of others, especially if he felt something was directed toward him. Steven had a need to feel in control and became agitated and anxious when he felt out of control.

There was no etiology for his diagnosis of acute ESRD, which occurred in October 2009. Upon meeting Steven for the first time in the outpatient dialysis setting, he immediately mentioned his anxiety about receiving treatment. Adjustment to the illness and the changes in lifestyle, including dietary and fluid restriction, were not easy for Steven. He was free in expressing how change was difficult for him. Establishing a trusting relationship with him was important in order for Steven to utilize the support that could be offered to him as he adjusted to living with ESRD.

During the first year of his illness, Steven discussed the strong emotions he experienced regarding the dialysis treatment. Statements of "I hate coming," "This has ruined my life," "I don't want to be here," and "There is nothing good about this" were often communicated. Occasionally, Steven would mention that he wanted to stop dialysis. Steven displayed a low tolerance with frustration and became hostile toward unit staff regarding waiting time, unit procedures, and nurses providing care.

To Steven's credit, he was aware of the difficulty he was experiencing in accepting his illness and he participated for a short time in the unit's patient support group. Expressing his feelings to other people on dialysis seemed to be somewhat helpful, but it was not enough. He had difficulty hearing the positive outlooks that the other patients shared.

Steven would ask all members of the interdisciplinary team if his kidneys would ever regain full function. His behavior became more hostile as the possibility for regaining kidney function appeared less hopeful. Steven also reported a more frequent depressive mood. He described periods of fatigue, sleeplessness, and feelings of sadness and hopelessness.

#### *Presenting Problem*

From the beginning, Steven was not adherent to his dialysis treatment regimen of 3.5 hours, 3 times weekly. Reviewing his treatment history (see Table 1) between October 2009 and October 2010, Steven missed an average of two to four treatments per month. In January 2011, seven treatments were missed. Steven had been frequently advised by all members of the interdisciplinary team about the consequences of nonadherence.

Steven and I discussed possible barriers that might be interfering with his dialysis schedule, such as his work schedule, transportation, or his anxiety toward needles. Steven continued to feel well and did not exhibit any negative physical symptoms caused by missing treatments. This latter fact was very important in attempting to understand why Steven may have undervalued dialysis. The interdisciplinary team and I were unsure what to do next.

During the first year, Steven and I developed a strong therapeutic relationship. Our relationship consisted of mutual acceptance, respect, understanding, and trust. The therapeutic relationship is a fundamental component of mental health care. It has been found to predict therapeutic treatment adherence and outcomes. The therapeutic relationship

**Table 1.** Number of Missed Dialysis Treatments

Month	Number of Treatments Missed
October 2009	0
November 2009	3
December 2009	1
January 2010	1
February 2010	3
March 2010	2
April 2010	5
May 2010	2
June 2010	4
July 2010	4
August 2010	3
September 2010	3
October 2010	2
November 2010	3
December 2010	4
January 2011	7
February 2011	4
March 2011	3
April 2011	4
May 2011	0
June 2011	1
July 2011	1

is the means by which a therapist hopes to engage with and effectively make change. In many ways, the relationship is the precursor to the concept of the working alliance; the rapport that develops between the therapist and the patient makes it possible to work purposefully in therapy (Cooper & Lesser, 2005).

We discussed the possibility of working on improving Steven's adjustment to dialysis. He was aware that he needed some assistance in learning to cope with living with ESRD and adjusting to the restrictive dialysis regimen.

#### *Session 1: Assessment, Experiential Avoidance*

This first session began with an assessment of the coping strategies Steven had utilized to manage his emotions toward dialysis. There was a brief discussion of the ACT model and an ACT handout, "Dissecting the Problem," was completed (Appendix A). The purpose of the handout is to develop an understanding of the problematic issue presently facing the patient. The problem is dissected into four categories: entanglement with thoughts, life-draining actions, struggle with feelings, and avoiding challenging situations.



The handout revealed that living with ESRD made Steven feel less than a whole person and not worthy of companionship. He displayed feelings of distress, frustration, and confusion toward his illness and dialysis treatment. When experiencing these emotions, Steven chose not to go to dialysis or reacted in a self-destructive manner (i.e., drank excessive fluid, smoked marijuana, and took his anger out on others).

We explored if Steven's behaviors were avoidance strategies he adopted to avoid his emotions toward dialysis and stay in control. In ACT, this behavior is defined as experiential avoidance, the act of avoiding unpleasant thoughts, emotions, and other private experiences (Flaxman, Blackledge, & Bond, 2011).

Included in the assessment was a discussion of Steven's dreams and hopes for the future. Steven would like to receive a kidney transplant, have a long-term committed relationship, and see his niece and nephew get married. We ended the session with a discussion that our future sessions together were an opportunity for Steven to learn and develop more positive ways of responding to his distress toward dialysis so that he could fulfill his dreams.

### **Sessions 2 and 3: Creative Helplessness, Contact with the Present Moment**

In these two sessions, we continued to discuss Steven's attempts to avoid unpleasant feelings toward dialysis (experiential avoidance) and explored if his current strategies of missing treatment were effective. From an ACT perspective, this stage of treatment is called creative hopelessness, a method designed to help the patient see whether their attempts to fix the problem have worked, which opens up the possibility of attempting alternative, more positive solutions.

The use of the creative hopelessness process tends to vary in duration and frequency. People who have extensive histories of using experiential avoidance, as with Steven, may need more time to work through the creative hopelessness process.

Steven and I had a lengthy discussion about his anger, which has been a problem for him throughout his life. In this session, we talked about the anger regarding his dialysis treatments, specifically. We discussed his tendency to blame others for his feelings of anger. He explained that instant gratification is necessary for him. The consequences or the pain he inflicts on others at that moment is insignificant. Steven stated that his anger is the reason why he had been arrested for assault in the past.

Despite his many years of counseling, Steven continued to verbally release his anger at the cause of his annoyance. Steven became frustrated and displayed his anger when there were excessive wait times to receive his dialysis treatments, unit problems, or insensitive staff. Steven believed these situations were personal attacks toward him and his solution was to leave the dialysis unit. The creative helplessness intervention was applied as we

explored his avoidance behavior of leaving the dialysis unit and discussed if this solution could have long-term physical consequences.

This discussion was not an attempt to change his feelings of frustration and anger toward these situations, but an exercise to make him question what his solutions cost him in terms of emotional energy, health, and time. The ACT therapist does not attempt to change the client's distressing thoughts or attenuate their distressing emotions, but focuses instead on increased behavioral effectiveness (Flaxman, Blackledge, & Bond, 2011). In response to our discussion, Steven stated, "I live in the moment and do not project into the future."

Since Steven stated he lives in the moment, the ACT commitment and behavior change strategy of contact in the present moment was introduced. Contact in the present moment is the ability to monitor more closely whether one's behavior is effective or ineffective at the moment.

Steven was presented with the idea of allowing himself to recognize his thoughts and behaviors in stressful situations. His initial response was "Why would I want to make myself feel uncomfortable?" Steven stated the intense feelings he experiences toward his illness make him feel it is just another thing wrong with him.

### **Session 4: Creative Helplessness, Willingness, Cognitive Defusion**

Steven was still missing dialysis treatments, but he stated he looked forward to our sessions and gave thought to our discussions. He acknowledged that he was beginning to understand how his solution of leaving dialysis when he is angry is ineffective. Steven noticed he sometimes has more difficulty breathing when he skips a treatment. However, change made Steven feel uncomfortable. He believed any attempt to change his attitude toward dialysis meant that the illness had taken control.

The next intervention was to increase Steven's awareness that his avoidance behaviors were not only problematic, but his negative thoughts were also holding him back from living a meaningful life.

Steven was asked to explore his values or goals in life. Steven stated, "Nothing in life is worthwhile; I have no goals." He believed living with ESRD will shorten his life expectancy, so having goals is pointless. This was an example of thoughts dominating his behavior. From an ACT perspective, this is called cognitive fusion. Cognitive fusion means being caught up in the thoughts and pictures in our heads so that we lose sight of the present moment or present experience (Harris, 2009). The concept of cognitive fusion may help explain why thoughts can become so threatening that individuals are prepared to engage in behavior that is detrimental to their well-being and quality of life to avoid them.

To introduce cognitive defusion, I challenged Steven on his statement that "nothing in life was worthwhile." Steven was asked the question, "What makes that thought really true?" He was asked to reflect on why he chooses to continue with dialysis if life was not worthwhile. Steven had no comment to my statements, but was deep in thought.

Cognitive defusion is the process where an individual learns to observe one's thoughts for what they truly mean, not what the mind says they mean (Eifert, Forsyth, Arch, Espejo, Keller, & Langer, 2009). In ACT, challenging irrational thoughts is an exercise for the patient to learn not to always trust the thoughts in their mind.

### **Session 5: Acceptance and Committed Action**

In this session, Steven stated he gave thought to our previous discussion about what he values in life. Steven admitted he wished for a better quality of life but was unsure what it meant or how to obtain it. We reviewed his values, what he would like in the future, and what he would like to achieve.

Steven had a long standing interest in receiving a kidney transplant, but had not made an attempt to start the evaluation process. He dreamed of receiving a kidney, which would relieve him from dialysis, but the fear of transplant failure, and the possibility of returning to dialysis, created a barrier to putting this plan into action. Steven believed that when life is going well, something bad always happens (cognitive fusion). We discussed how he had allowed the fear of a transplant failure to create a barrier to moving forward and having the opportunity to live a better life. A comparison was made to the avoidance behaviors he implemented regarding his dialysis regimen to demonstrate that the procrastination of putting a plan into action was another avoidance behavior.

In order for Steven to show improvement in adherence to his dialysis prescription and commit to action toward fulfilling his life's values, he would have to be willing to begin the process of acceptance. Acceptance is the willingness to experience distressing emotions that are encountered in the process of behaving consistently toward one's values (Flaxman, Blackledge, & Bond, 2011). It is the opposite of control and avoidance and was a major treatment target. Acceptance and willingness is about the control of choices and actions, not about thoughts and feelings. It is not an outcome goal but a process goal (Blackledge & Hayes, 2001).

Exposure practice provides an important opportunity for patients to develop the willingness to experience distressing situations. They are encouraged to choose to be open to their experiences and to respond nondefensively. This intervention helps foster cognitive defusion so that cognition does not get in the way of life-directed goals.

In Steven's case, the exposure exercise for him was to choose a different approach if the wait time for dialysis treatment was excessive. He was advised to be mindful of the emotions he felt, but to choose the solution that would be beneficial to his physical health. This introduced the

concept of choices. The requirement of having to receive hemodialysis treatment may not have been a choice for Steven if he wanted to live, but he had the choice to decide how he responded to the discomfort.

### **Session 6: Goal Establishment**

As Steven arrived at this session, I immediately commented that his mood and affect appeared happier. Steven described how he had been receiving compliments from his family and coworkers regarding the same, but could not understand why. He did not believe he was acting any differently, but he appeared pleased that others had noticed a change.

During the week, Steven had given some thought to what his future goals might be. In addition to a kidney transplant, he determined that he wanted to work toward going on vacation, reestablishing his driver's license, obtaining a car, and renting an apartment rather than living in a room.

Steven stated that he realized that he couldn't fight this illness any longer. It was costing him too much in the way of emotional energy. It was explained that his feelings were a form of acceptance. Steven thought that acceptance meant he had to like receiving dialysis. It was clarified that acceptance is not changing or reducing feelings but allowing them to be there without a struggle. Acceptance is the willingness to stay with discomfort while also actively and intentionally choosing to engage in life-directed behavior (Eifert, Forsyth, Arch, Espejo, Keller, & Langer, 2009).

Steven discussed a conflict that occurred between himself and the dialysis unit nurse regarding his target weight during a previous dialysis treatment. He stated he became angry and was aware that he may not have handled himself in an appropriate manner. This was the first time Steven was insightful and assumed some responsibility for his behavior. It appeared from Steven's behavior that his ability to experience distressing emotions toward dialysis had improved. In addition, he was able to recognize his behavior in the moment (contact with the present moment).

### **Session 7: Commitment**

By this session, Steven had been 100% compliant with his dialysis treatment for that month. Steven stated, "I am trying to do the best I can and do what I need to do" and "I look at the bigger picture." He stated his desire to keep his body in good shape. He felt better physically and used the kidney transplant goal as motivation. Positive changes were demonstrated by the change in Steven's behavior (not missing treatments) and his positive thoughts (acknowledging he is doing the best he can). It appeared his focus had shifted to future goals rather than concentrating on the distressing emotions toward dialysis.

The remaining sessions focused on committing to a plan of action to move Steven toward reaching his selected goals. Commitment refers to the behaviors or actions taken to fulfill one's life-driven values or goals (Flaxman, Blackledge, & Bond, 2011).

### Sessions 8–15: Committed Action, Maintenance

The last 8 sessions of working with Steven focused on obtaining his stated life goals. Steven had completed various tasks: he made arrangements for a kidney transplant evaluation and began looking for an apartment. Steven took more of an interest in his physical well-being. He made several telephone calls to his physician and scheduled the appointments necessary to address his medical issues.

Steven stated that he still became angry while in dialysis but he had chosen not to react to these unpleasant situations. In ACT terms, he was allowing himself to experience his frustration and anger, but chose another solution.

There were times during our sessions that Steven experienced higher levels of frustration due to medical complications or environmental stressors. Discussions were focused on Steven becoming aware of his automatic negative thoughts and emotional reactions to these stressful situations. These setbacks were potential causes for missing dialysis treatments and interference with his plans of working toward his future goals.

### DISCUSSION

In this case study, the use of ACT was successful in improving treatment adherence with one person's prescribed hemodialysis regimen and in improving quality-of-life scores. Fifteen sessions were held for approximately 45 minutes to 1 hour over a 5-month period. Sessions were held during dialysis treatment or in a private office prior to treatment at weekly intervals, except for weeks in which there were schedule conflicts.

Desired therapeutic outcomes were: 1) increased treatment adherence to Steven's prescribed dialysis regimen and 2) an increase in Steven's quality of life. Increase in adherence was measured by a decrease in the number of dialysis treatments that were missed during a month. Over the 5-month period in which these therapeutic sessions were held, treatment adherence improved: 100% compliance occurred in 1 month and only one treatment was missed in 2 consecutive months (Table 1). The possibility exists that 100% treatment adherence will be difficult to maintain. Work or family schedules and the inability of the dialysis unit to provide schedule flexibility are variables that may affect adherence.

**Table 2.** KDQOL-36 Scores

Date	Symptom/ Problem List	Effects of Kidney Disease	Burden of Kidney Disease	SF-12 Physical Composite	SF-12 Mental Composite
03/07/11	70.83	53.13	31.25	34.45	30.48
07/28/11	66.67	62.50	37.50	33.15	52.53
Mean	71.38	38.50	38.65	36.89	45.41
Change	-4.16	9.37	6.25	-1.30	22.05

To measure an increase in quality of life, the Kidney Disease Quality of Life (KDQOL)-36 questionnaire was administered. The KDQOL-36 is a self-reported quality of life measure for people with ESRD. It is a 36-item survey with 5 subscales: physical functioning, mental functioning, burden of kidney disease, symptoms and problems, and effects of kidney disease on daily life. Scoring algorithms are used to calculate scores from 0 to 100, with 100 representing the highest quality of life. According to The Dialysis Outcomes and Practice Patterns Study (Mapes et al., 2003), low health-related quality of life scores were associated with a higher risk of death and hospitalization. As physical and mental functioning scores decreased, the risks of death and hospitalization rose significantly. Scores are compared to means and standard deviations in terms of age and gender.

The KDQOL-36 was administered to Steven at the first and last sessions. The most significant change was shown in Steven's mental function score (Table 2). His score increased 22.05, from 30.48 in Session 1 to 52.53 in Session 15. Steven's score was higher than the mean score of 45.41. There was a slight decrease in scores for how the effects and burden of kidney disease have affected Steven's quality of life. The effects of the disease subscale rose 9.37, from 53.13 to 62.50; the burden of disease subscale rose from 31.25 to 37.50, a change of 6.25.

Other positive outcomes that can be noted were Steven's willingness to let go of the struggle to control his illness (acceptance). This was demonstrated by the increase in his treatment adherence while still experiencing the distressful emotions toward dialysis. Furthermore, there was a shift in Steven's focus from his intense feelings toward dialysis to contemplating and working on future goals. Steven completed various tasks that were part of his committed action plan and actively made choices to address distressful situations in the dialysis unit in a different manner.

Before beginning ACT therapy, Steven's thoughts and behaviors were rigid and inflexible. By Session 15, it appeared Steven was willing to think about his distressful situation and conduct his behavior more appropriately. In ACT terms, Steven became psychologically flexible, resulting in the ability to live a more meaningful life even in the presence of undesirable thoughts and emotions.

This case study demonstrated the use of only a few of the many ACT techniques and tools (Table 3). Experiential avoidance was used to assess Steven's problematic avoidance behaviors. Creative helplessness was the process used to create awareness of Steven's problematic behaviors and unsuccessful outcomes. Mindfulness was used to bring about awareness of Steven's emotions and behaviors in the present moment (contact with present moment). Challenging irrational thoughts was used to create confusion in the validity of Steven's thoughts (cognitive defusion).

An exposure exercise was suggested to assess Steven's ability to handle distressing emotions without reacting to them, and to select alternative, more positive solutions to his distressing situation. Life goals and values were discussed to shift Steven's focus away from his illness. The discussion and planning of tasks were the interventions used to create the action plan to fulfill Steven's chosen values or goals.

This case study has some limitations. ACT was applied only to one patient and this is the author's first attempt with this therapeutic intervention. Steven's avoidance behavior was the most difficult issue to address. Therefore, the process of creative helplessness was used in more than one session. In addition, more emphasis could have been placed on the self-as-context process, which comprises the self-defining characteristics that are developed by what one is presently thinking, feeling, and remembering. Steven defined himself as not being worthy of companionship and being less than a whole person. This was not addressed in the sessions. In addition, ACT has many other tools and techniques that can be used as interventions. This case study lacks the demonstration of all these tools, such as various handouts, metaphors, and paradox.

An ESRD diagnosis and the restrictive dialysis regimen it requires create the possibility of unexpected psychosocial or medical complications that may interfere with the patient's focus on working toward life goals. An important recurrent task for social workers is to assist patients in coping with these barriers and to recommit to their values and goals.

One of the target goals of the ACT theory is working toward a life driven by fulfilling one's values. Not all cultures place value on living toward the individual's life-driven goals. In some cultures, values and goals are developed in relation to family rather than the individual. Furthermore, ACT's theoretical framework is grounded in language and cognition. Different linguistic cultures have specific language for certain ideas and concepts, which produces differentiated ways of thinking.

Steven's depressive symptoms before our sessions are reflected in the low mental function subscale in the KDQOL-36 survey. Further research could explore the use of ACT therapy for people with ESRD who display depressive symptoms or low KDQOL-36 scores. There may be practical advantages to acceptance and life-valued actions as a method of dealing with the psychological challenges of this chronic illness.

This appears to be the first study in which ACT was attempted with a person with ESRD. It outlines the usefulness of the ACT model not only for adherence to dialysis regimen and quality of life, but as a possibility to address depression, the difficulties patients experience with excessive dialysis wait times, and other unit problems. It is hoped that this case study will spur additional research on the effectiveness of ACT regarding the adjustment to living with ESRD.

**Table 3.** Treatments per Session

Session Number	ACT Core Therapeutic Process	ACT Intervention
1	assessment of avoidance strategies	experiential avoidance
2–3	experiential avoidance contact with present moment	creative helplessness introducing mindfulness
4	experiential avoidance cognitive defusion	creative helplessness challenging thoughts
5	cognitive defusion acceptance	challenging thoughts exposure exercise
6	values acceptance	life goals willingness/choices
7	acceptance	willingness/choices
8–15	committed action	completing tasks



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## APPENDIX A

*Dissecting the Problem*

This form is to help gather information about the nature of the main challenge, issue, or problem facing you. First, please summarize, in one or two sentences, what the main issue or problem is:

Second, please describe, in one or two sentences, how it affects your life, and what it stops you from doing or being:

Regardless of what your problem is—whether it is a physical illness, a difficult relationship, a work situation, a financial crisis, a performance issue, the loss of a loved one, a severe injury, or a clinical disorder such as depression—when we dissect the problem, we usually find four major elements that contribute significantly to the issue. These are represented in the boxes below. Please write as much as you can in each box, about the thoughts, feelings and actions that contribute to or worsen the challenge, problem or issue facing you.

**Entanglement with Thoughts:**

What memories, worries, fears, self-criticisms, or other unhelpful thoughts do you dwell on, or get “caught up” in, related to this issue? What thoughts do you allow to hold you back or push you around or bring you down?

**Life-draining Actions:**

What are you currently doing that makes your life worse in the long term: keeps you stuck; wastes your time or money; drains your energy; restricts your life; impacts negatively on your health, work, or relationships; maintains or worsens the problems you are dealing with?

## Benefits and Barriers: An Exploratory Study of Nephrology Social Work Field Education

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An important aspect of the profession of social work is the requirement of at least 900 hours of a “field placement” internship for all masters-level social worker (MSW) students as part of their education in accredited U.S. schools of social work (Council of Social Work Education, 2008). The goals of this project are to increase the number of South Carolina dialysis units that offer MSW students field placement opportunities, and to explore professional and personal benefits and barriers for dialysis social workers assuming the role of field educators. Ten social workers participated in the project’s interviews about the benefits of and barriers to being an MSW field educator. Ultimately, 6 social workers contracted with the University of South Carolina to accept students for field placement in dialysis units, and 2 students completed their field placement in dialysis units for the academic year 2010–2011. The MSW-level social workers reported several barriers to being field educators: their relationships with the USC College of Social Work, organizational climate, organizational functioning, social work caseload and tasks, professional identity, and general concerns about students. Social workers also identified possible areas benefiting from being social work field educators: organizational climate, patient care, workload, professional obligation, intrinsic rewards, and the fact that a dialysis unit could be a rich learning environment for MSW students.

### INTRODUCTION

Dialysis patients have multiple psychosocial barriers to treatment (Browne, 2006), which were the impetus for including a masters-level social worker (MSW) in every dialysis unit by mandate of the Centers for Medicare & Medicaid Services Conditions for Coverage in 1976 and, most recently, in the 2008 revision of the conditions. For the foreseeable future, every dialysis unit in the United States needs to have an MSW as part of its interdisciplinary treatment team to help patients ameliorate psychosocial barriers to positive chronic kidney disease outcomes.

An important aspect of the profession of social work is the requirement of at least 900 hours of a “field placement” internship for all MSW students, as part of their education in accredited U.S. schools of social work (Council of Social Work Education, 2008). This allows the student to get hands-on experience working with clients and communities, trains the student about a unique population, and it is also, sometimes, a pathway to future employment after the student graduates. MSWs serve as field educators for students, providing supervision and learning experiences for the student over the year that the MSW student is in that setting.

In the field of nephrology social work, it is important, for several reasons, that dialysis social workers act as field educators. First, it exposes MSW students to the psychosocial issues of chronic kidney disease (CKD), and the role of the social worker in an interdisciplinary team ameliorating those issues. As CKD increases as a public health crisis in the United States, it is important that awareness of this disease, and its interventions, be known to as many professionals as possible, including future social workers (who may end up working in any setting after graduation).

The second reason why dialysis social workers as field educators are important is to train student interns for the enhancement of the profession. As the incidence and prevalence of CKD continues to increase, and the clinical social work mandates of the new Conditions for Coverage necessitate smaller social worker-to-patient ratios, the kidney community will need more nephrology social workers than ever. Having MSW students trained in dialysis social work could lead to a higher interest in the profession of nephrology social work after graduation and enhance the workforce. A newly graduated social worker with dialysis experience is helpful for the acting social worker, the dialysis unit, and the patients. Therefore, training this “next generation” of dialysis social workers through field education is important.

A third reason why field educators are important is that the practice can be helpful for the social worker and dialysis patients. Having an “extra” social worker in the dialysis unit allows for the field instructor to enhance the services provided to patients. The patients and dialysis team can benefit from a student intern in multiple ways. It can also be helpful for the social worker to assume the tasks of a supervisor, and this supervisory experience can be a great addition to a social worker’s skill set and resume.

Despite the advantages of becoming field placement instructors, many may be hesitant to do so because of a lack of training or experience in that role, perceived lack of benefits, high caseload, or inappropriate task responsibility. The goals of this project were to increase the number of South Carolina dialysis units that offer MSW students field placement opportunities and to measure benefits and barriers for dialysis social workers assuming the role of field educator. The motivation was that, prior to this effort, there were no

dialysis units in the entire state being used as field placement sites for MSW students by the University of South Carolina (USC) College of Social Work. With the continuation the 2008 Conditions for Coverage mandate to include of MSWs in every dialysis unit, there is a dire need to train the next generation of nephrology social workers through field placement opportunities in these units. This project explored the barriers and benefits of being a field educator

in order to advance further study and increase the number of MSW student field placements in dialysis settings.

### METHODS

#### Study Design

As there were zero students in dialysis field placements at USC prior to this project, the first step was to encourage students to choose their field placements in dialysis

**Figure 1.** Flyer Given to MSW Students at the USC Field Fair

### Top 7 Reasons to Choose A Dialysis Center For Your Field Placement in 2010–2011

1. **Money, money, money**—There are thousands of dialysis units across the United States, and all need a Master’s level social worker in them. Having experience in a dialysis unit can help you find a job in any state after graduation. The regulations mandating an MSW in every dialysis unit were just revised in 2008, and will not be changing anytime soon (the last regulations were in effect for more than 30 years), so social work practice in a dialysis unit is a very promising area for employment of new MSW graduates that is NOT impacted by the economy.
2. Dialysis units are the **only** healthcare setting in the U.S. that has a Medicare mandate that *requires* that every dialysis center have an MSW on its interdisciplinary team. If you are interested in working with an interdisciplinary team, it is great experience to work with such a team of nurses, doctors, patients, technicians, and dietitians—you do this every day in a dialysis unit.
3. If you like working with/think you will like working with chronically ill adults and their families, a dialysis unit can provide you with extensive experience in micro, macro, community, or policy social work—depending on your interest. Dialysis social workers have to do everything, from grief counseling, to case management, to community advocacy and linkages, to counseling family members (and a million more things in-between).
4. Dialysis units are open evenings and Saturdays, and may be able to accommodate a flexible schedule for your field placement.
5. You will be supervised by an MSW.
6. At the College of Social Work, Assistant Professor Teri Browne is overseeing a special project on field placements in dialysis units in SC. She has more than 12 years experience working in dialysis units, and will be your field liaison for the year, and you will have uniquely structured tasks, training and supervision in dialysis social work, and work with fellow students also in dialysis unit field placements—you will not be alone!
7. There are field placement opportunities in dialysis social work all across the state! Dialysis units in the following cities are eager to have students: Charleston, Columbia, Easley, Greenville, Mt. Pleasant, Spartanburg, Summerville, & Walterboro. See the field office for details of the field placement sites available.

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settings, and to find social workers willing to be field instructors and who would share their experiences about why they were currently not instructors. To recruit field placement candidates, information was provided to MSW students about opportunities in dialysis centers at the college's annual Field Fair. At the fair, a display board with information about nephrology social work and the National Kidney Foundation Council of Nephrology Social Workers (CNSW) was used, and materials from the local NKF office were provided to students. In addition, prospective students were also given verbal information about kidney disease and opportunities for field placements in dialysis settings, along with a handout about why they should choose a dialysis center (see Figure 1).

The investigators collaborated with the college's Field Placement Office during every step of this project. The primary investigator (PI) agreed to serve as the faculty field liaison for the dialysis field placements, which consisted of three visits to each field placement for the year, as well as assistance with any issues or concerns that the student, field educator, or field placement office might have during the academic year.

To recruit social workers into the study, and to be field educators, a letter was mailed to every dialysis center in the state of South Carolina, inviting them to be instructors for the USC. Information about this opportunity was also presented at local CNSW meetings, and distributed on the local CNSW e-mail listserv.

#### *Data Collection Procedure*

The PI traveled to dialysis units across the state to conduct semi-structured interviews of interested nephrology social workers. Lunch and a \$30 Visa gift card, approved by the USC Institutional Review Board, were provided to the social workers as compensation for their participation in this project.

**Figure 2.** Discussion Guide for Social Worker Interviews

#### **Dialysis Social Worker Discussion Guide Questions**

- Have you ever been a field placement supervisor before?
- Generally, do you think that social work field education is important? Why/why not?
- Specifically, do you think that dialysis-specific social work field education is important? Why/why not?
- Why are you not currently a social work field educator?
- What are the barriers to being a social work field educator (in South Carolina specifically, and in the U.S. in general)?
- What would you like to see included in a dialysis social work training toolkit for field placement educators and students?

Interviews with dialysis social workers examined the rewards and costs of being field educators from their perspective (Peleg-Oren, Macgowan, & Even-Zahav, 2007). The interviews explored two questions: 1) What barriers exist that prevent placement of MSW interns in dialysis units? and 2) What benefits could be enhanced to increase MSW internships in dialysis units? A qualitative approach to this research allowed for in-depth exploration of the social workers' perceived barriers and benefits related to being field educators. As there is currently no dialysis-specific literature about this topic (and very little literature in the broader field of social work education), this qualitative approach was an appropriate way to start building this knowledge base. It also allowed for a rich exploration of field instructors' experiences and viewpoints. See Figure 2 for the discussion guide for each interview.

This research was guided by the Investment Model theoretical framework (Peleg-Oren, Macgowan, & Even-Zahav, 2007; Rusbult & Farrell, 1983). This model has been used to examine job commitment and job satisfaction. The model tests the degree to which social workers are psychologically attached to or invested in their job, and in previous research by Peleg-Oren et al., the model was used to examine social workers' commitment to intern supervision. Specifically, the model measures the workers' subjective perception of their job commitment through the pathways of rewards, costs, degrees of investment, and availability of other job opportunities. We did not use the entire model, but focused on the two aspects most salient for this study: the benefits or rewards (positive aspects of supervising interns) and barriers or costs (aspects of supervising interns that were viewed as negative). We believed that these two aspects of the model would be weighed most heavily by social workers who might consider working with interns in dialysis units. This model posits that nephrology social workers' commitment to supervising students may increase as they perceive rewards from being a field instructor. Such

rewards could be intrinsic or extrinsic, and come from the agency itself, the type of agency, the relationship between instructor and intern, or a sense of mission to give back to the profession. To measure these variables, we developed a semi-structured interview guide of open-ended questions to measure the perceived benefits and barriers.

#### *Data Analysis*

The social worker interviews were taped and transcribed. Interview transcriptions were coded and analyzed using Atlas Ti (6.2) software. We used an inductive approach in this project because so little is known about the attitudes of nephrology social workers who might want to supervise interns. The Investment Model was used to help strategically focus the interview questions, but the codes and findings emerged naturally from what the social workers said. The interviews were independently coded by two researchers, then discussed. Any codes that were similar or redundant were collapsed. We reported the most frequently used codes.

## **RESULTS**

#### *Enrolling Students and Social Workers*

Ten social workers participated in the interviews. Ultimately, 6 social workers contracted with the USC to accept students for field placement in their units, and 2 students completed their dialysis unit field placements in the academic year 2010–2011. Many more social workers were interested in being field educators. However, in 2010, the university was not able to contract with one large dialysis organization for such placements because of legal issues that the state and the dialysis corporation had with the contract language.

## **RESEARCH QUESTIONS**

#### *What Barriers Exist that Prevent Placement of MSW Interns in Dialysis Units?*

Social workers identified barriers to being a field educator related to their relationship with the College of Social Work, organizational climate, organizational functioning, social work caseload and tasks, professional identity, and general concerns about students.

#### *Relationship with the USC College of Social Work*

Respondents agreed that one primary reason why they were not field placement supervisors was because the USC College of Social Work had not previously contacted dialysis social workers to place students in their clinics. Social workers stated "no one [at the college] ever asked," and "it was just [that] nobody ever really brought it to our attention."

#### *Organizational Climate*

Social workers identified organizational climate variables that were barriers to being field educators. These included a lack of organizational support for social workers and

dialysis centers not valuing the social work role. This lack of support made some social workers hesitant to take on the task of being a field educator. Some social workers commented: "Well, you know, we have a long history of not being supported"; "they [administrators] think we don't do nothing"; and "the doctors don't know or appreciate what we do."

#### *Organizational Functioning*

Social workers suggested that there were some other organizational barriers to being a field educator, primarily a lack of a system to have social work students intern in dialysis units. For example, one social worker shared: "the system, being a medical system, is set up to take students from medical fields, particularly nursing ... but if they have social work students, it is of no concern to them." Some dialysis units also did not have flexibility to accommodate students on weekends or evenings, as may be needed by some students.

#### *Social Work Caseload and Tasks*

Some social workers were interested in being field educators; however, a high caseload or inappropriate clerical tasks precluded them from accepting students. One social worker mentioned that "the social workers are stretched and overwhelmed ... if they had more time they would be interested." Another social worker commented, "It's unfortunate because I really wanted to do it and my center director was approving of it. My regional director was just worried about the time constraints because I have so many other things that I do ..." Some social workers agreed that they feared that they would not have the time to attend to an MSW student because they were already overwhelmed with high caseloads and clerical tasks.

#### *Professional Identity*

Some social workers did not think that being a field educator was a primary part of their professional identity. Respondents simply had not thought about being a field instructor, or just hadn't made any effort to become one. One respondent recalled a bad experience she had as an MSW student in her own field placement, and did not want to provide students with less-than-exceptional field placement opportunities.

#### *General Concerns*

The final barrier to being a field educator was that the respondents had some general concerns about the social work students who would spend the academic year in their dialysis units. Respondents raised concerns that students might be too immature, that the students may not like a dialysis setting, and that the work experience could get monotonous for some.

### What Benefits Could Be Enhanced to Increase MSW Internship Placements in Dialysis Units?

Importantly, social workers also identified possible benefits that could come from being a social work field educator. These areas included the organizational climate, patient care, workload, professional obligation, intrinsic rewards, and the fact that a dialysis unit could be a rich learning environment for MSW students.

#### Organizational Climate

Social workers also identified organizational climate variables that could help augment field placements in dialysis settings. Several social workers mentioned that they had a supportive environment in their clinic to have an MSW intern, including the support of regional managers. This included an autonomous work environment that would accommodate student training.

#### Patient Care and Workload

Several social workers posited that having an MSW student in their dialysis clinic could improve patient care. Students would be able to work closely with and follow up more frequently with patients to which social workers may not be able to fully attend, and patients may have their needs met better by working with social workers and students. Students may also be able to do interventions, such as home visits, when social workers may not be able. In addition, students could help with clinical paperwork, and help patients with concrete needs, ameliorating a portion of the social worker's workload.

#### Professional Obligation

In regard to the possible benefits of being an MSW field educator, respondents discussed that doing so might fulfill a professional obligation. Social workers mentioned that being a field educator would be a way to "give back" to the profession, as all MSW social workers must complete hundreds of hours of field placement service as part of their education. Respondents thought that being a field educator would allow them to share wisdom with social work students; one respondent mentioned that she "wanted [students] to get a really good experience." One discussed a good experience she had with her own field placements, and wanted to pass that on now that she was a social worker.

#### Intrinsic Reward

Social workers suggested that being a field educator might provide them with intrinsic awards, and that it would be gratifying to be a part of an intern's development. Building relationships, and training and mentoring students may be rewarding. One respondent posited that working with a student may be like training a new social worker: "... and you meet a lot of the new social workers coming in and I got to spend a lot of time, do a lot of training with them, and I find it extremely rewarding."

### The Dialysis Unit Is a Rich Learning Environment

The final benefit of being a field educator discussed by respondents was that a dialysis unit could be an ideal location for an MSW field placement. Dialysis clinics provide complex clinical situations for social work students, and opportunities for mental health or substance use assessments that can augment classroom learning. One social worker summarized:

And we all have different scenarios, as you know, with different kind[s] of family dynamics going on, and depression, and it seems like we have a mixture of all the situations you have in social work schooling. We have it right here in the clinic.

#### DISCUSSION

This project is the first of its kind in kidney disease literature related to possible benefits of and barriers to MSW field placements in dialysis settings, as well as establishing a program for field placements in dialysis by a college of social work. Because of the novelty of the program, one limitation of this research is the small sample size, derived from only one Southeastern state. Future work could attend to a larger survey of nephrology social workers about field education specifically; the CNSW does frequent online caseload, salary, and membership surveys and could add questions about field placements, if the Council would like to explore this line of research further. As this was a qualitative study breaking ground on new information about nephrology social workers and field placement, the sample size is a necessary limitation. Another limitation is that the study only included dialysis social workers, not kidney transplant social workers (who should also be supported and encouraged to be MSW field educators related to kidney disease). However, in the state of South Carolina, there is only one kidney transplant center, which is 113 miles away from USC, so transplant social workers were not chosen as part of the sample because of logistics.

Despite the small number of social workers interviewed and the small number of dialysis centers that accepted students for field placements during the duration of this project ( $n = 2$ ; the college started with zero dialysis units offering field placement), this effort resulted in significant possibilities for students, the college, and nephrology social workers in the state. Because of this project, the college is now able to place MSW students in more than 50 dialysis units in South Carolina, North Carolina, and Georgia. This benefits the college (as it provides novel field placement settings for students), MSW students, and the profession of nephrology social work.

As part of this research, social workers identified important barriers to being a field educator. Most notably, concerns about large patient caseloads and inappropriate clerical tasks were brought up in this context as a barrier to accepting a student for a field placement. This concern echoes

previous work by Merighi and Ehlebracht (2004a, 2004b, 2005) and the CNSW (Browne & Merighi, 2011; Browne, Merighi, & Herold, 2008; Merighi, Browne, & Bruder, 2010) about the impact of high caseloads and inappropriate tasks that nephrology social workers face in the United States.

#### Recommendations for the Profession

As the only Medicare-mandated practice setting for MSWs, nephrology social work needs more research and projects related to field placement education of MSW students in dialysis and kidney transplant settings. As field placement is such an integral part of social work education, dialysis clinics are ideal settings to expose more social work students to kidney disease and its psychosocial components. Serving as field educators may result in several different benefits to social workers as well, including the benefits explored in this study.

Nephrology social workers can liaise with colleges of social work across the country to explore training MSW students for field placements. As there may not be very many faculty members in schools of social work who are themselves familiar with kidney disease or dialysis (and may not be aware that every dialysis setting must have an MSW on its interdisciplinary team), social workers should not wait for colleges to approach them to be field educators. Indeed, a major barrier to being a field educator, as voiced in this study, is that social workers were never asked to be field educators. Colleges of social work can explore establishing relationships with nephrology social workers in their communities, and learn more about dialysis and kidney transplant settings as a possible field placement sites. Colleges may also want to come to local CNSW Chapter meetings to present about such possibilities.

Social workers may want to work together as field educators, providing some common curriculum for their MSW students, and involve students in different dialysis centers in quality improvement or patient care projects. The CNSW will be offering an online toolkit related to nephrology social work field placements in the future that can help facilitate such internships.

The CNSW and others need to continue efforts related to addressing high patient caseloads and inappropriate clerical tasks that social workers face so that they can effectively train the "next generation" of nephrology social workers. Social workers and others who hold key positions in large dialysis organizations can help with possible obstacles colleges may face when trying to place students in dialysis settings and encourage their social workers to take on students. Some companies already have policies and procedures for working with social work students.

#### CONCLUSION

This project is highly relevant to the field of nephrology social work, as field placements are an essential part of every social worker's education. It behooves nephrology

social workers to increase the number of dialysis units used as field placement sites. This not only "gives back" to our profession, but also can result in a cadre of uniquely dialysis-trained social work graduates, some of whom may choose to practice nephrology social work because of their exposure through field placements. Further research on dialysis and kidney transplant field placements can also identify other professional and personal benefits of being a field instructor that may motivate more dialysis social workers to be field instructors.

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## Lived Experiences: Hemodialysis and Adherence

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*This qualitative study, entailing face-to-face, individual, tape-recorded interviews with a convenience sample of 22 hemodialysis patients, examines their lived experiences regarding adherence to the hemodialysis treatment regimen. The 7 open-ended questions capture patients' experiences with coming to treatment, taking medications, and restricting fluids. Content analysis identifies the primary patterns in the data—the themes, words, concepts, and terms that prevail in the responses (Patton, 1990). The findings point out the multidimensional aspects of adherence and patient struggles and challenges, and they may open doors for further research that can identify effective interventions.*

### INTRODUCTION

The questions posed in this study lie within the field of nephrology. What are the factors that influence how a patient responds to the hemodialysis provider's efforts to deliver efficient, effective, life-sustaining health care services, and, at the same time, respect the patient's right to make choices? Although it is expected that patients will do what is required of them to get well or stay alive, often this does not happen for a variety of reasons. People have the right to make choices and sometimes make choices that prove, in retrospect, to be unwise. People sometimes choose not to follow doctors' orders and thus are often labeled "nonadherent." The right to self-determination and the concept of patient choice can and do conflict with caregivers' efforts to deliver prescribed hemodialysis treatment (O'Brien, 1990). This topic is important because nonadherence contributes to mortality and morbidity (Leggat, 2005), increases health care costs (Kimmel et al., 1998), impedes the ability of health care systems to effectively manage chronic diseases (Morgan, 2000), and impacts resource allocation (Atkins & Fallowfield, 2006; Christensen & Johnson, 2002).

Historically, social workers have been the ones called upon to address compliance, which is defined as submitting to a request or demand, and adherence, defined as being attached, devoted to, and supportive of an act or opinion (McKechnie, 1983). In the delivery of hemodialysis services, nephrology social workers are members of a multidisciplinary team that is responsible, along with the patient, for developing a plan of care that is in the best interests of the patient while following the ESRD Survey and Certification Program Guidelines set by the Centers for Medicare & Medicaid Services (U.S. Department of Health & Human Services, 2008).

While respecting the patient's right to self-determination, social workers are called upon to assess, educate, intervene, and assist patients in making informed decisions about their care as part of the care planning process. Knowing the subjective or "lived" experiences of hemodialysis patients and understanding the many dimensions of adherence may enable social workers and the multidisciplinary team to develop effective interventions.

A review of the literature reveals several studies that address adherence to medication regimens, keeping appointments, sharing responsibility for adherence with physicians, the concept of the team approach to adherence, and determining the most effective and efficient treatment regimen. The results are often contradictory. Even quantitative research presents a challenge in identifying factors that influence adherence. A qualitative study conducted in Australia by Williams, Manias, and Walker (2008) addressed the issue of how patients and health professionals view medications and medication adherence. Twenty-three patients with diabetic kidney disease and 16 health care professionals in diabetes and nephrology clinics participated in focus groups. The researchers found that consumers were not convinced of the value and safety of taking their medications and some had difficulty obtaining their medications due to inadequacies in the health care system. The focus of the professionals was on medication adherence. The researchers concluded that the professionals needed to acknowledge the barriers faced by the consumers in order to open up lines of communication that could serve to facilitate medication adherence, promoting the conclusion that patients and health care providers are a team and the providers need to listen to patient concerns.

This researcher perceives a distinction between compliance and adherence as a distinction between the "patient," who is expected to follow the doctor's orders, and the "person," whose medical decisions are made in the context of living life. Compliance research tends to look at the patient (Bame, Peterson, & Wray, 1993; Kaveh & Kimmel, 2001; Morduchowicz et al., 1993; Takaki, Wang, Takigawa, & Ogino, 2007) and paints a portrait of noncompliance based on factors such as attendance, gender, marital status, and interdialytic weight gain as prescribed by doctors. Adherence research tends to look at the person (Gordon, Leon, & Sehgal, 2003; Kugler, Vlaminc, Haverich, & Maes, 2005; Leggat, 2005; Moran, Christensen, & Lawton, 1997; Morgan, 2000; Tijerina, 2006) and ask "why" questions, e.g., "Why are treatments shortened and/or missed?"; "Why do patients not follow diets?"; "Why do patients make the choices they make?" Compliance and adherence research have sought, ultimately, to forward

theoretical frameworks for further study and to create effective interventions to address patients not following doctors' orders.

O'Brien (1990) brought attention to the concept that compliance had no "gold standard" by which it could be measured. She conducted a 9-year longitudinal study that touched on the concept of patient self-determination in which she raised the distinction between ritual and reasoned compliance. She defined ritual compliance as passively following the treatment regimen to the letter and reasoned compliance as active—tailored and modified to meet the physical, social, and emotional needs of the patient (perhaps a forerunner of adherence). Ironically, at the end of the 9 years, O'Brien found that patients who died in the first 6 years had the highest compliance while those surviving the 9 years had the lowest compliance, with both numbers being statistically significant. Patients alive after 9 years reported in open-ended interviews that they had learned where they needed to be strictly compliant and where they could stretch the limits (reasoned compliance).

In a mixed-methods study ( $N = 168$ ), Gordon, Leon, and Sehgal (2003) looked at skipped and shortened treatments, drawing a distinction between reasons for shortening and skipping treatments and general nonadherence. They found that medical problems, life situations, and transportation were the primary reasons for skipping and shortening treatments, and that males and Blacks (males and females) were most likely to skip and shorten treatments. Women reported logistical problems (e.g., child care, family obligations) for shortening treatments and new patients reported technical problems (e.g., transportation) for skipping treatments. These results also support the multidimensional complexity of the concept of adherence.

In a qualitative study ( $N = 26$ ) using phenomenology, a way to look at one's subjective experiences and world view, Tijerina (2006) examined nonadherence among Mexican-American women living in Texas and determined that poverty, length of time on dialysis, immigrant status, perceived identity losses, and family dysfunction impacted adherence. Three years later, she analyzed the same data from a social constructivist perspective, which looks more at the meaning of results, and concluded that poverty, length of treatment history, and whether the patient was an immigrant were factors that appeared to most impact adherence (Tijerina, 2009). Tijerina, a social worker, pointed out that this social constructivist approach facilitates social workers' understanding how these Mexican-American women understood their reality as hemodialysis patients, and that the person-in-environment approach is most effective in working with this population. While Tijerina's results are not generalizable to either women or Mexicans, she provides a viable lens through which patients' lived experiences can be examined.

To frame this study, this writer utilized social constructionist theory as it is defined in the discipline of sociology.

Berger and Luckman (1966) published a classic tome on the sociology of knowledge that introduced the concept of social constructionism. This theory is described as similar to Schutz's phenomenological sociology in which the researcher focuses on the meaning of social experiences (Franklin, 1995). Bengtson, Burgess, and Parrott (1997), gerontologists, declared that social constructionism acknowledges how people create and maintain social meanings in their everyday lives. A "reality" is produced by individual behavior, which then structures people's lives. The message is clear. One cannot understand another's world view without "walking a mile in their moccasins."

The social construction of diagnosis and medical knowledge addresses the socialization of medical providers, the practices of the health care system, and corporate needs—concepts that are often distinctly different from the interests and reality of patients. Bringing social constructionism directly to the medical field, Brown (1995) described the social construction of diagnosis and illness for providers in three different ways. The first version focuses on how medical sociologists define social problems. Brown's second version of constructionism addresses the issue of medical social control as it is targeted at the human being who is viewed as a potential agent of social action. The social work value of client (patient) self-determination is often challenged as the concept of adherence is vigorously promoted to patients. Brown's third version of constructionism states that scientific facts are the result of scientists' ideas and actions as well as their public efforts to promote their work. The social construction of adherence must be examined from several perspectives. It is socially constructed by patients, physicians, providers, and family members.

While much of social constructionist theory is borrowed from sociology, Witkin (1999) declares that social constructionism is congruent with social work and reflects the values and mission of social work. This congruence obligates social work to lead in translating social constructionist thought into research and practice. He speaks for the patient when he declares "that those who are marginalized in society have a perspective that is valuable for the rest of us to hear" (Witkin, p. 7). The social work profession must be prepared to challenge oppressive social constructions and expose the myth of the "expert professional" who claims to have "privileged knowledge" (Witkin).

### METHODOLOGY

This study was conducted in three New York state hemodialysis centers in Brooklyn, the Bronx, and Suffolk County. The qualitative data were collected as part of a larger mixed methods study ( $N = 125$ ) in order to explore in greater depth how adherence is perceived by patients. Seven open-ended questions were asked of 22 patients, a convenience sample, which was chosen based on their willingness to participate. The open-ended questions were included in every fifth questionnaire package and presented to the patients as an additional data collection instrument. However, not

every fifth person was interested. These questions allowed patients to express their lived experiences and their perceptions of adherence and its impact on them, providing their answer to: How do the lived experiences of people on hemodialysis impact adherence?

The study excluded patients who were on home dialysis, under 18 years old, previously on peritoneal dialysis, recipients of failed transplants, incapable of giving informed consent, and incapable of responding to verbal questions. This researcher approached patients at the dialysis centers, explained the study to them, and extended a written invitation to participate. Informed consent was obtained from those agreeing to participate. These documents were translated into Spanish to increase the number of potential participants. A Spanish-speaking colleague obtained informed consent and administered the questionnaire to Spanish-speaking patients.

The 7 open-ended questions were:

1. *Tell me what it is like for you to be on hemodialysis.*
2. *Tell me what it is like for you to come for dialysis treatment and stay on it for the time required.*
3. *Tell me what it is like for you to take all of your medications as prescribed.*
4. *Tell me what it is like for you to restrict your fluid intake.*
5. *Tell me about some of the times that you have been unsuccessful in managing your treatment regimen.*
6. *Based on your experience, what would you tell someone new to dialysis about the challenges of their treatment?*
7. *Is there anything else you would like to say about your experience as a person on hemodialysis?*

Their responses were tape recorded and transcribed by this researcher. The data were analyzed, utilizing content analysis to identify the themes, words, concepts, and terms that were prevalent in the responses (Patton, 1990). The qualitative component sought to categorize the lived experiences of hemodialysis patients as they cope with medication, fluid weight gain between runs, and attendance issues related to the hemodialysis treatment regimen.

### RESULTS

This study was designed to capture the lived experiences of people on hemodialysis. The goal of qualitative research is usually understanding, more so than prediction or inference (Drisko, 1997). Understanding what hemodialysis patients experience as they struggle to be adherent is the purpose of this study. The 22 patients answered all 7 open-ended questions. Twelve (55%) of the 22 were less than 65 years of age. Seventy-three percent ( $n = 16$ ) had at least a high school diploma. Twelve were women. The racial/ethnic breakdown was 55% Black ( $n = 12$ ), 27% White ( $n = 6$ ), and 18% Hispanic ( $n = 4$ ). Eighteen had incomes of less than \$25,000 per year. Fifty-nine percent ( $n = 13$ ) lived alone.

Several themes emerged from the data that clearly spoke to the lived experiences of the patients. The most powerful theme to emerge was the challenge of fluid control—not being able to drink as much as they desired. More than half of the patients reported that restricting fluids was hard.

"Very hard, very hard, very hard, very hard, because, sometimes I want some water and I see what place the home attendant is and I hop in the kitchen," confesses Myrtle, a 67-year-old retired seamstress, about sneaking a drink of water.

"Restricting your fluid is difficult 'cause you get thirsty," acknowledges Matt, grandfather of four.

Adam, a young man, admits, "That's the hardest because sometime(s) you just want to gobble down, drink, drink, drink, and that—that's the hardest."

"Very difficult. Um, I love, you know, drinking a very tall glass of cold water and, you know, having to restrict the amount I take in, it's not something that I enjoy. That I know fluid intake is a big deal in my dialysis treatment so I try, you know. I have to maintain it in order to, you know, have a successful treatment. I'm always thirsty. You know, I feel drained and parched and I don't like that feeling," laments Mae, a young mother of two.

Difficulty, frustration, pain, and stress—two-thirds of the patients expressed these themes in their responses. Most realized that hemodialysis is something that must be done, no matter how frustrating or difficult it is.

Says Janet, grandmother of two, "It is very hard, very hard, very hard ..."

"It's a frustrating situation but you have to live with it," reports Juanita, a mother of two teenage boys.

For young Simone, whose nursing career came to a halt, "It can be stressful at times. And it's draining."

"I don't like it. It bothers me," reports Roy, a retired baker.

"Frustrating ... it changed my life completely. I was a career woman, had a wonderful job, doing extra college classes ... an active mom. After I got on dialysis, everything changed. It was all about coming over here, taking care of my health. It's difficult when all the stuff that you love to eat is no longer something that you can eat," reports Mae, the young mother of two.

"It's frustrating ... but you have to live with it," sighs Judy, a former teaching assistant.



With so much focus on difficulty, frustration, pain, and stress, one may wonder how patients survive. It gets easier with time, a theme emerging from that of frustration.

“At first it was hard, but now I’m getting used to it ...” responds Gabriel, an elderly gentleman who is quite spry.

Matt states, “It’s not easy, but I do it, you know? I just do it. Got used to it.”

Emma, a middle-aged seamstress, says, “It’s not a problem. I don’t complain.”

For Ross, a “young” 84-year-old minister, “No problem. I come all the time. As long as the schedule is set, I’ll be there to meet it all the time.”

The life-sustaining aspect of hemodialysis is evident to patients, despite the difficulty, frustration, pain, and stress.

“If I don’t do my dialysis, then I will die,” concludes Terri, a retired home health aide, who also finds dialysis “very hard.”

“I need it in order to survive,” replies Juan, a Hispanic man with diabetes.

While Mamie, a Jamaican woman, offers, “It’s a blessing for me. I truly need dialysis and I come here with a positive attitude and I try to keep that attitude, and it’s really working out very well for me.”

Ross responds that dialysis is “No problem. I comply with whatever is set for me.”

Aaron, a father of two, says it well: “If I don’t do my dialysis, then I will die. So I just make it good for myself and my kids.”

“Sometimes I feel like I’m, like I’m contained or incarcerated but I got used to it as part of my life’s plan until I get a kidney. I got used to it because I want to stay alive and keep doing what I’m doing,” states Jeff, who still manages to work in construction.

“But, it’s a life-saving—it’s a live-saving—situation. You can continue to do whatever normal things you do, and it’s beneficial to the body and to the soul and for your life,” declares Angel, father of three.

The main theme that emerged regarding living with medications was that taking medications as prescribed was good for them and would help them get better. Secondary themes reflected the ease of taking medications for some patients and the problems encountered by others, such as the number and size of pills, timing phosphate binders, forgetting to take medications, and some difficulty in obtaining medications.

Harriet, a young woman who has had diabetes since age 12, offers, “I take all my medica-

tions as prescribed because, uh, like I said, I want to get better. And that’s going to make me get better.”

“It’s not bad at all. I’m used to it and it makes me feel better,” says Roy.

“It’s not an issue because my medicine is what makes me get better, so if I don’t take it, I get sick,” affirms Natalia, a young Hispanic mother of two.

Seven reported that taking medications was easy, no problem.

“Natural and easy. I do it every day. No problem with that,” announces Ross.

“Oh, it’s not a problem taking the medicine. I just take them, you know. It’s like it’s set in my head, you know, like clockwork and I just take them,” reports Aaron, father of two teenage boys.

Five of the 12 patients pointed out some of the problems they encounter in taking their medications.

Mae, reports, “Frustrating. It’s hard, you know, sometimes, to remember, um, ‘cause I take a lot of medications, so, it’s not something I enjoy ...”

“My problem is the renagel. Don’t tell them, but I never take it. [laughs] The rest of the stuff I take,” confesses young Adam.

“I take 35. I counted them once,” laments Roy.

Many dialysis patients experience some barriers, obstacles, and problems. While some are simply overwhelmed by the whole experience, others have specific challenges that they have encountered—some more serious than others. While 9 patients flatly denied having any problems (e.g., “None, at no time,” “I never had a problem,” “No, not at all,” “Well, thank God, in the two years I’ve been on dialysis I haven’t had no problems and I’ve been doing great.”), many patients did express that they have encountered problems that caused them great concern.

“The holidays, weekends, office parties ... you know, regular home parties,” laments Queenie, a clerk, about events made difficult by her condition.

“Oh Lord, sometimes in the morning I get up and I stick my finger. I like to see my sugar in the ones but when it gone up in[to] the twos and threes, I got the cold sweat[s] and I shake and I shake,” cries Myrtle.

“Oh, yes, a few times I hadda have the fistula; I had to get a balloon blown up in the fistula,” Matt complains.

“Well, there are times when my body starts to itch. Well, I guess that was because my phosphorus level was rising,” reports Juan.

“Well, just this week here itself, I’ve been having a lot of low blood sugars. It was two days out of the week that I wasn’t able to wake up and I thank God for my sister being home, that she was able to call the ambulance to come and help me out because the sugar level just dropped low regardless of what I did,” laments Harriet.

“Maybe—when I first started dialysis and I had a tube coming out of here and I went to the gym and went swimming and I almost died. And my body, was, you know, had chills and stuff and I had to go to the hospital,” confesses Jeff.

“Oh! The only problem I ever had was when I was working, trying to go to work and be on time and still, still [had to] come here for all the hours,” declares Gus.

The lessons learned by hemodialysis patients are many. These are lessons that allow them to advise new patients to help them avoid some of the pitfalls. Patients are only too willing to give advice, another emerging theme. The advice that they would give to patients new to dialysis covered a wide range of subjects. Eleven patients pointed out urgently that dialysis keeps one alive.

“Please, just come with a positive attitude. Know that this dialysis is going to help you and continue to let you live for however long. If you do what you are supposed to do, dialysis can be very successful [for] you,” declares Judy.

“Keep your head up, hang in there. Not as bad as what you think—life still goes on, you know. And just look at all the positive ways that you still are here. You could be gone,” advises Emma.

Eight subjects advised new patients to go to their treatments.

Adam muses, “What can I say? I’d feel sorry for the guy. For one thing—what else can I say, you know? Just that—sit back and take your treatment. That’s all, you know.”

“Just tell them make sure they go to their treatment and try not to skip none. Listen to the doctor and just go to your treatment,” warns Aaron.

Simone says, “First of all, you have to go, even though you don’t want to go, but you have to go, because, you know, it’s going to help you. Just be patient, that’s all.”

Four pointed out that it is hard.

“I would tell them it’s not easy, it’s hard, but to stay on their daily regimen and never cut their time,” cautions Janet.

“It’s difficult when all the stuff that you love to eat is no longer something that you can eat. You just have to make the sacrifice to deal with the change,” laments Mae.

Three cautioned about fluid restrictions.

Myrtle declares, “Stick to your treatment and stick to your diet. I can’t tell them nothing else. Stick to your treatment. And don’t drink too much fluid ‘cause when you get on that machine and start getting cramps you call [out] a lot of bad words.”

Coping strategies were the focus of patients who sought to assist others to adjust and survive. Six subjects addressed their efforts to restrict their fluids, offering suggestions.

“It’s not easy during the summer, but it’s necessary, ‘cause I don’t want to go forward one and take two steps back. So my fluid intake is very important to me. No problem, you know. Just eat a lot of ice instead of drinking fluids. Just munch on some ice. It’ll last you longer and, you know, it quenches your thirst,” offers Juan.

Matt has found a system. “Well, in the summertime, and I get thirsty, I have an old juice jar. I think it’s about six ounces. That’s how I measure my drink.”

“Oh, I’m good at that. I’m very good at that. When I’m thirsty, I suck on ice,” boasts Harriet.

## DISCUSSION

The lived experiences of the hemodialysis patients in this study reflect the many dimensions of adherence. Being on hemodialysis and coming for treatment is hard, frustrating, challenging, as well as life sustaining. Medication adherence is contingent upon remembering to take it and having the medication. Restricting fluid intake is hard. Sucking ice and measuring fluid help control intake. Some of the reasons for unsuccessful management of the hemodialysis treatment regimen include: poor attendance, itching, uncontrolled glucose, catheter infections, work, holidays, and weekends.

Twelve of the 22 patients responded that they took their medications because they were good for them and would make them better. Williams, Manias, and Walker (2008) point out that many patients doubt the safety or effectiveness of their medications, which was not the case with this sample. Among the problems raised were: remembering to take medications, an issue addressed in a study by Atkins and Fallowfield (2006), the number of pills prescribed, and, specifically, the phosphate binders. Two patients admitted that they did not take their phosphate binders. The 7 patients who reported no problem with taking their medications described it as a part of their routine. They had accepted it as part of their lives.

The results regarding fluid adherence reflect the struggles many patients face, along with the good feelings they have when they succeed. Thirteen of the patients reported that restricting fluids was hard. They were always thirsty and felt parched, drained, and deprived. Only 4 patients

reported that restricting fluid was not hard, 3 of whom cited the dire consequences of fluid overload, a reflection of Yokoyama et al.'s (2009) results that people who believe that benefits outweigh barriers are more adherent to fluid restrictions. Six patients addressed their efforts to restrict their fluids, offering suggestions such as sucking ice and using a 6-ounce glass to measure fluids.

Thirteen patients reported that they are used to coming and staying for treatment, and found it was not a problem. Nine found it hard, and 5 simply stated that hemodialysis was what kept them alive so they came. Several of those who found it hard also acknowledged that it kept them alive.

Kaveh and Kimmel (2001), continuing to pursue a "gold standard" (a way or ways accepted universally by which to measure adherence), proposed total time adherence as one measure of treatment time adherence. This researcher opted to utilize this measure as it captures the composite concept of attendance, which had formerly been broken down into skipped and shortened treatments, two distinctly different concepts (Kimmel et al., 1995).

The limitations of this study lie in the small sample size and lack of generalizability. Another limitation may be the influence of the interviewer on patients' responses, always a factor in qualitative studies. Future research can include repeating this study with a larger sample that incorporates a wider range of demographics—additional ethnic groups, rural communities, people who speak languages other than English and Spanish—which could yield results that could provide additional strategies to enhance adherence. This study looks only at in-center hemodialysis patients. Studying peritoneal dialysis or home hemodialysis patients could yield very different results. A quantitative study could look at the issues identified in this study to see if they are predictive of nonadherence. In the context of social work and the National Association of Social Workers (1996) Code of Ethics, knowing more about the lived experiences of hemodialysis patients can facilitate the design of effective interventions. Both seasoned and novice nephrology social workers can benefit from the results of this study. Focusing on the lived experiences of in-center hemodialysis patients, along with the standard assessment forms currently used, can provide a richer picture of the person who is the patient. This can facilitate "buddying," support group formation, and general patient education, leading to effective interventions to address nonadherence.

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## The Feasibility and Patient Acceptance of a Treatment Support Group in the Dialysis Setting

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*A structured treatment support group was conducted with 2 caregivers and 6 people on dialysis who reported feelings of isolation and episodic non-psychotic depression. The patients were medically diagnosed with end-stage renal disease and are currently undergoing in-center hemodialysis for their treatment modality. Participants in the group were recruited on a volunteer basis from 4 DaVita Dialysis clinics located in Fountain and Colorado Springs, CO. The facilitating social workers utilized cognitive behavioral therapy and relaxation breathing techniques for the group. Self-reports were utilized to measure the successful outcomes of the group. The reports indicate that patients perceive group therapy in the dialysis setting positively, and that it is feasible to conduct group therapy in the dialysis setting.*

### INTRODUCTION

People diagnosed with end-stage renal disease (ESRD) who elect in-center hemodialysis as their treatment modality often experience mild to severe depression (Finkelstein & Finkelstein, 1999; Levy & Cohen, 2000; U.S. Renal Data System, 1999). Perhaps their depression stems from loss of independence, as they are required to devote an average of 3 hours to a single treatment of dialysis, 3 days a week; loss of kidney function; or an altered lifestyle, such as the inability to work full time, fatigue, or a perceived reduction in quality of life. Moreover, people with ESRD are often reluctant to take yet another medication, such as an anti-depressant, to alleviate their depressive symptoms, which may be attributed to the fact that many people with ESRD take upward of 10 to 12 pills a day, such as phosphate binders, to sustain their lives (Braveman & Cohen, 2002).

Further, people on dialysis are less likely to receive treatment for depression, despite being inundated by medical professionals. One possible cause of this discrepancy is that people with ESRD typically report somatic complaints that emulate depressive symptoms, such as fatigue, sexual dysfunction, and insomnia (Cohen et al., 2002). Additionally, practitioners often hesitate to prescribe anti-depressants to people with ESRD due to concern of medication antagonist effects (Cohen, Germain, & Tessier, 2003). However, the absence of a depression treatment modality can have a significant impact on both the quality of life and medical outcomes of people on in-center hemodialysis (Finkelstein & Finkelstein, 1999).

### CHARACTERISTICS OF DEPRESSION AND ITS PREVALENCE IN PEOPLE ON DIALYSIS

Depression is the most common psychological problem encountered in people with ESRD (Finkelstein & Finkelstein, 1999; Kimmel, 2000; Kimmel et al., 2000; Levy & Cohen, 2000). It is imperative to clarify what is meant by depression. Although depressive symptomatology is frequently encountered in people on dialysis, to meet the Diagnostic and Statistical Manual (DSM)-IV criteria for a major depression diagnosis, 5 or more of the following symptoms must be present: anhedonia, fatigue, inattentiveness, inappropriate guilt, psychomotor agitation or retarda-

tion, significant weight loss or gain, depressed mood, and/or recurrent thoughts of death or suicide. Typically, the symptoms are accompanied by imbalanced sleep patterns, appetite, and libido. Studies that have employed the Beck Depression Inventory (BDI)—a standard self-administered questionnaire commonly used in mental health practice to screen people for depression—have reported markedly similar findings (Kimmel, 2000; Kimmel et al., 2000). These studies convey that between one-third and one-half of people on hemodialysis have scores positing at least a moderate degree of depression (BDI scores of 11 or greater). Furthermore, Wuerth et al. observed that when these individuals were then evaluated by a trained psychiatric interviewer for the occurrence of clinical depression, 85% of people on dialysis with BDI scores of 11 or greater met the DSM-IV criteria for major depression and had scores of 17 or more on the 21-item Hamilton Depression Scale (unpublished observation).

### CORRELATION BETWEEN DEPRESSION AND MORTALITY RATES

Several studies have shown the negative impact depression has on outcomes in people with ESRD. In a study by Hedayati and Finkelstein (2009), 98 people with ESRD initiated on hemodialysis were followed prospectively. Within the cohort, 21 out of 26 clinically diagnosed depressed individuals compared to 31 out of 72 nondepressed individuals had died or were hospitalized at 6 months with a hazard ratio of 2.1. Further, researchers determined that the association of morbidity remained after adjustment for several demographic factors, including age, time on hemodialysis, and the number of comorbid conditions.

Many other studies have confirmed the increased risk of mortality in the depressed ESRD population. For instance, the Pathways Study, a longitudinal prospective cohort study of people with diabetes, showed that out of 110 people with stage 5 chronic kidney disease in the 4,000-person study, 22% had major depression, which was associated with a 3-fold greater risk of death compared to those with either no or few depressive symptoms (Young et al., 2010). A large 15,000-person study conducted by Soucie and McClellan (1996) evaluated the risk factors that were associated with

death in the first 90 days after initiation of hemodialysis and found that they included age, male gender, smoking, congenital heart failure, and clinical depression. One possible explanation may be that people who are depressed are less likely to adhere to their medication regimens. Researchers examined medication adherence in people on hemodialysis compared to transplant recipients and concluded that people on hemodialysis were more likely to be depressed, and, in multiple-regression analysis, the variance in depression was the only significant predictor of medication adherence in both groups (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009).

### DIFFICULTY DIAGNOSING DEPRESSION IN THE ESRD POPULATION

One potential difficulty in diagnosing depression in this population lies in the challenge of differentiating between typical somatic symptoms and overt depression. A study by Watnick, Wang, Demadura, and Ganzini in 2005 validated two different depression scales, the BDI and the Patient Health Questionnaire 9, against the gold standard Structured Clinical Interview for DSM-IV (SCID-IV) in people with ESRD. Analyzing the BDI specifically, a cutoff of 10 or greater is used in the general population to diagnose possible depressive disorder. Conversely, this study showed that in the ESRD population a cutoff value of 16 or greater had sensitivity toward depression and a specificity of 91% and 86%, respectively; thus, indicating that a value of 15 or lower did not accurately reflect the ESRD cohort's depressive symptomatology. The specificity rates portend that depression is prevalent among the population; given this data, one can predict that these individuals would thereby benefit from such interventions as a treatment support group specifically targeted to alleviate depressive symptomatology.

### A REVIEW OF THE LITERATURE: THE BENEFITS OF DEPRESSION TREATMENT SUPPORT GROUPS IN THE HEMODIALYSIS SETTING

There is a paucity of research literature available to assess the effectiveness of depression related to treatment support groups in the hemodialysis setting. However, one randomized study conducted in Brazil found that an intervention group of 41 participants compared to a control group of 44 participants exhibited significant improvements of their depressive symptomatology (Duarte, Miyazaki, Blay, & Sesso, 2009). Researchers utilized cognitive behavioral group therapy (CBT) over the course of 9 months while the control group received the usual treatment offered in the dialysis unit. In both groups, the BDI, the Mini International Neuropsychiatric Interview (MINI), and the Kidney Disease and Quality of Life-Short Form (KDQOL) questionnaires were administered at baseline, after 3 months of intervention or usual treatment, and after 9 months of follow up. The intervention group exhibited significant reduction of the burden of renal disease, sleep,

quality of social interaction, overall health, and the mental component summary of the BDI overall scale and the MINI. Considering these results, researchers concluded that group CBT is an effective treatment of depression in chronic hemodialysis patients.

Another study conducted by Cukor (2007) found CBT to be a beneficial treatment for a cohort of 16 people comorbidly diagnosed with ESRD and depression. Cukor engaged the individuals in either group or individual therapy over the course of 15 weeks. Cukor found that two themes emerged within the group: people believe that depression is part of the illness and that disability prevents them from enjoying life. The goal was to have participants attempt modified versions of the activities they used to enjoy, and a combination of cognitive restructuring and behavioral assignments were used. All participants exhibited a significant decrease in their BDI-II scores at the conclusion of treatment. The mean BDI-II score decreased from 28.9 to 18.5 at the end of the treatment and was recorded at 18.8 at a 3-month follow up (possible scores range from 0 to 63, with higher scores representing an increase in depression), indicating both a significant and sustained reduction in depressive affect.

A study published in 1986 concluded that support groups in the hemodialysis setting contributed to the longevity of people diagnosed with ESRD (Friend, Singletary, Mendell, & Nurse, 1986). Each person was asked, prior to beginning dialysis, to join a group of similarly ill people to discuss common problems of stress, quality of life, and adjustment to changes in their daily lives due to ESRD. Those who joined the group did so at the start of their dialysis. Group activities were designed to teach new coping skills through group discussions and social functions. Activities, however, were not to be identified with group psychotherapy as group members were strongly opposed to psychotherapy. Critical issues of death and dying, fear of the machine, and difficulty with fluids or diet management were discussed, with each member sharing his/her own problems or successes around these issues. Social functions included summer picnics and annual Thanksgiving dinners. Food served at meetings and other functions was used to teach dietary compliance and to expose group members to a wide variety of dietary choices.

Out of the total sample of 126 people on hemodialysis, 88 were designated as participants in the group and its social activities and functions during the 10-year study. The remaining 38 people were designated as non-participants and did not take part in the group activities. A total of 30 people (22 group participants and 8 non-participants) survived the duration of the study. The results, established by the Kaplan-Meier survival curves, indicated that a higher proportion of group participants lived longer than the non-group participants. A second survival analysis, the Cox proportional hazard regression model, was performed to determine whether group participation was related to survival when controlling for 13 covariates: family history of

renal disease, psychiatric problems, blood urea nitrogen, creatinine, age, sex, religion, education, marital status, family support, work history, psychiatric history prior to entering dialysis, and year of entry into dialysis. The analysis indicated that group participation remained strongly and independently related to survival. Researchers noted, however, that survival was also strongly related to lower levels of creatinine and less strongly to the absence of psychiatric problems on dialysis and higher blood urea nitrogen.

### PURPOSE OF THE STUDY

The purpose of our study is to facilitate a treatment support group for people diagnosed with ESRD who have reported experiencing depressive symptoms. Moreover, we would like to establish a protocol to be used in all DaVita Dialysis clinics that incorporates the use of treatment support groups aimed at reducing depressive symptomatology. In order to establish the value of the proposed protocol there are 2 questions this study aims to answer: 1) Will people on hemodialysis participate and respond positively to a treatment support group? 2) Is the facilitation of a treatment support group feasible? It is our hypothesis that the people on hemodialysis who participate in the treatment support group aimed at reducing depressive symptomatology will perceive the group as beneficial to their overall well-being and that it is feasible to incorporate such a group within the dialysis setting.

### STUDY DESIGN

All 6 people on hemodialysis were recruited on a volunteer basis from the 4 DaVita Dialysis clinics in Colorado Springs and Fountain, CO. Participants were asked to remain at their designated clinic for a period of 6 weeks (the duration of the study). People who had been diagnosed with depression related to psychosis were not recruited, nor were those who reported feelings of suicide or who reported experiencing suicide ideation within the past 6 months. This decision was based on the social workers' determination that these individuals lacked the psychological stability to participate in the group, and that their instability would likely pose a hindrance to other group members' experiences. Further, the sample was recruited from the hemodialysis treatment modality population. People receiving peritoneal and home hemodialysis were not recruited in the study. Each of the participants was considered to be in "good enough health" (established by the center's clinical coordinator) in order to be transported to the group's location and participate in group activities.

Participants at the four clinics often expressed feeling overwhelmed by the amount of paperwork and questionnaires presented to them on a continual basis. Thus, screening tools were not used to establish depression; rather, self-reports describing feelings of anhedonia, fatigue, inattentiveness, inappropriate guilt, psychomotor agitation or retardation, significant weight loss or gain, and depressed mood present 30 days or longer, were gathered through

"chair-side" conversations with 3 resident social workers. Prior to agreeing to participate in the group, many patients expressed concern over the loss of family time and stated that this factor would prevent them from participating, thus, they were encouraged to have their caregivers participate in the group (2 caregivers agreed and remained active throughout the duration of the group). Moreover, the social workers felt that caregiver participation was crucial to successful outcomes as they were able to offer primary support to the patients in an effort to allay their depression.

The length of the study was once per week for 6 consecutive weeks and each session lasted for 1.5 hours; the study took place off-site, apart from the 4 dialysis units; and each session was facilitated by 3 resident social workers. Demographic information was not collected, nor was unrelated health information. However, we did ask participants to consent to access their medical records to gain information regarding medications and past medical problems in the event that ambulatory services were needed off-site. To answer the first question (Will people on hemodialysis participate and respond positively to a treatment support group?), we monitored each member's participation frequency in the group discussions, their willingness to engage with other group members, their tendency to remain on topic, their feelings about the group following its completion, and whether they would be willing to participate in the group again. These variables were considered to indicate participants' positive response to the group, as participation was seen as an integral component to the maintenance of the group. If individuals exhibited an unwillingness to participate in the topics of discussion or lacked interest—which was measured through the person's level of attentiveness—in the topics, then the social workers would perceive these behaviors as negative responses (refer to Table 1). Lastly, if individuals were unwilling or expressed disinterest in participating in the group again, this, too, would be seen as a negative response.

This information was obtained through self-disclosure in a sensing session that was hosted by the 3 facilitating social workers at the sixth and last session. The sensing session lasted one-half hour following the conclusion of the last session, wherein 4 questions were posed verbally to the group: What are your feelings toward the group? Which topic did you find especially helpful? Do you feel as if the group has contributed to your overall well-being? Would you participate in the group again? The answers were recorded manually by one of the social workers.

In order to answer the second question about the feasibility of a treatment support group, we asked participants about their modes of and accessibility to transportation and the ease of being transported to the location of the treatment support group. Our concern with transportation and its relation to feasibility stemmed from the lack of city and personal transportation expressed by many of the participants. Further, transportation was the only external feasibility

variable that we could control via offering each of the participants city bus passes. This information was obtained throughout the course of the group, as we wanted to ensure that participants did not feel over-burdened, which could possibly lead to an exacerbation of their depressive symptomatology.

Medical devices, such as blood pressure monitors, and questionnaires, such as the BDI or the KDQOL, were not pertinent to the case study because we were not measuring depressive symptomatology; therefore, they were not used. Prior to the initiation of the group, we obtained consent from each of the 3 facilitating administrators at the 4 dialysis clinics to proceed with conducting the group; further consent was not necessary. Moreover, all 6 participants and 2 caregivers were provided with a confidentiality form and a form of consent prior to the start of the initial meeting. The forms were read aloud by a facilitating social worker and each person was asked to sign both forms. Additionally, the only compensation provided to the patients and caregivers were free one-way bus passes, which were disseminated upon request.

### LIMITATIONS

Interaction of selection and treatment were potential threats to our design, as we recruited participants on a volunteer basis. Hence, the participants may have had increased motivation to accept the treatment and exemplify higher rates

of engagement and participation compared to their non-volunteering counterparts. Further, the Hawthorne effect may have also been a potential threat, considering that the participants possibly exhibited socially desirable behaviors as they were well aware that their behaviors were being monitored by the facilitating social workers. Moreover, the time constraint of 6 weeks was not nearly long enough to determine the efficacy of the cognitive behavioral therapy methodology in the reduction of depressive symptomatology, thus we were precluded from assessing the patients for depression following the conclusion of the study. Lastly, our decision not to utilize depression inventory scales, such as the BDI or the KDQOL, prohibits us from extending our results to the reduction of the patient's depressive symptomatology; rather, the results are only relative to the assessment of positive regard and feasibility.

### METHODS

Social workers recruited people on hemodialysis with flyers and verbal discussion while they received their dialysis treatments. They explained the purposes of the group in detail and answered questions regarding the group. Individuals were called by a social worker 1 day prior to each session to ensure attendance and to verify that they had access to transportation. Participants were provided with a snack at each session that resulted in a cost no greater than \$5 per patient. Each session covered methods designed to

**Table 1.**

Topic of Discussion	Technique	Participant Response
Introduction of group participants and social workers. Explanation of CBT and its effectiveness in the reduction of depression.	Explanation and introduction of diaphragmatic breathing	6 people on hemodialysis and 2 caregivers remained actively engaged and attentive to the topic
How thoughts affect your mood	Diaphragmatic breathing	6 people on hemodialysis and 2 caregivers remained actively engaged and attentive to the topic
Continuation of how thoughts affect your mood	Introduction and explanation of progressive relaxation technique	5 people on hemodialysis and 2 caregivers remained actively engaged and attentive to the topic
How your activities affect your mood	Progressive relaxation technique	6 people on hemodialysis and 2 caregivers remained actively engaged and attentive to the topic
Continuation of how your activities affect your mood	Diaphragmatic breathing	6 people on hemodialysis and 2 caregivers remained actively engaged and attentive to the topic
How contacts with other people affect your mood	Progressive relaxation technique and diaphragmatic breathing	6 people on hemodialysis and 2 caregivers remained actively engaged and attentive to the topic; 5 of the patients and 2 caregivers requested that the social workers facilitate another group in the very near future



reduce depressive symptomatology (refer to Table 1). All of the participants were encouraged to participate irrespective of the nature or topic of the specific sessions. At the end of each session, the facilitating group leader instructed the participants in a diaphragmatic breathing exercise, progressive relaxation technique, or both.

### RESULTS

The results regarding our first question (Will people on hemodialysis participate and respond positively to a treatment support group?) are as follows: All of the participants reported positive feelings about the group and relayed that they wanted to participate in the group once more. Two of the patients verbally disclosed an increase in self-insight, whereby they came to recognize their depressive symptoms and were able to attribute their symptoms to negative thoughts. One of the male patients, who exhibited few self-efficacious behaviors—asking the social worker to pay his bills, requesting that the social worker schedule his doctor's appointments, and requesting the social worker to arrange for his transportation to and from dialysis—prior to his participation in the group, reported and exhibited a greater amount of self-efficacious behaviors—whereby he was paying his bills, scheduling his doctor's appointments, and arranging for his transportation—toward the latter three sessions. Additionally, 4 of the participants verbally reported increased levels of physical activity and an increase in internal motivation. Based on these results, we conclude that people on hemodialysis will react positively to a treatment support group, and that such a group may benefit people on hemodialysis.

The results regarding our second question (Is the facilitation of a treatment support group feasible?) are as follows: As mentioned earlier, all of the participants were required to secure their own mode of transportation to the specified location. On one occasion, a patient missed the group session due to a lack thereof. Of the 6 patients, 2 requested bus passes each week beginning the fourth week of the group. The remaining patients either drove themselves or had the ability to afford increased transportation costs. Neither patient disclosed feelings of burden regarding transportation or transportation-related costs. Further, we were able to secure the location for the sessions free of charge, which was provided by a physical rehabilitation facility located in Colorado Springs, CO. In addition, costs resulting from the provided snacks were minimal and were absorbed by DaVita Dialysis. Based on these findings, we resolve that it is feasible to initiate, maintain, and continue offering a treatment support group at DaVita Dialysis.

### DISCUSSION

The positive results of this case study indicate that people receiving dialysis treatment at DaVita Dialysis in Colorado Springs and Fountain, CO, may benefit from a treatment support group targeted to alleviate depressive symptomatology. Although we cannot extend our results to the reduction in depressive symptoms, we can conclude

that patients regard a treatment support group positively and are willing to participate in the continuation of such a group. We can also conclude that the adjunct of a treatment support group is feasible within the hemodialysis treatment setting, and thus can be incorporated as part of the overall treatment modality. However, to assess the benefit of a treatment support group in reducing depression it would behoove future researchers to conduct a pilot study wherein they employ the utilization of depression inventory scales.

We must also note that future studies would need to take into account other feasibility variables such as high caseloads, high social worker-to-patient ratios, dialysis unit coverage, and inappropriate clerical tasks. Renal social workers are often so overburdened with inappropriate clerical duties that finding the time to engage in tasks that benefit patients is challenging. However, we assert that the more effort we put into tasks that directly benefit patients, the more likely it is that our positions within the dialysis setting will be seen as crucial to the outcomes of patients and our respective dialysis units and that the expectation to exert energy into menial clerical tasks will be quelled.

Moreover, recruitment efforts should not only come from social workers, but other health collaterals as well. For instance, nurses, technicians, and dietitians should offer this resource to individuals reporting or experiencing depression. This mutual effort will increase the likelihood that a patient will enlist in the treatment group cohort. Nevertheless, the case study provides evidence that a treatment support group incorporated within the dialysis setting is feasible and may be beneficial to people with ESRD.

It is hoped that if the personnel (social workers, physicians, nurses, and facility administrators) caring for people with ESRD in the dialysis setting are made increasingly aware of the possible alternative treatment options available for those exhibiting depressive symptomatology, treatment support groups can be devised and incorporated within the treatment modality to diminish at least some of the patients' suffering.

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**SOCIAL WORK ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION  
2012 SPRING CLINICAL MEETINGS  
MAY 9–13, 2012**

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<sup>1</sup>DaVita Inc., Denver, CO, USA
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University of Missouri-Columbia and Dialysis Clinics Inc., Columbia, MO, USA
- 15 Evaluation of Transplant Education in 500 Dialysis Centers in 21 States: Are Dialysis Patients Making Informed Treatment Choices?**  
Amy Waterman, Christina Goalby, Emily Herrington, Shelley Hyland;  
Washington University, Saint Louis, MO, USA



1. USE OF TALKING CONTROL SUPPORT THERAPY IN CHRONIC HEMODIALYSIS PATIENTS RESULTS IN HIGHER PATIENT SATISFACTION SURVEY RESPONSE

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Hemodialysis patients struggle with non-compliance that may be secondary to depression. Talking control (TC) is a cognitive behavior technique described as most comparable to a befriending relationship that has studied in depressed older populations in the primary care setting. The purpose of this study was to evaluate the effect of TC in a chronic hemodialysis population. Methods: TC consisted of general conversations about lifestyle without the specific intent of education change. Patients were randomly approached to participate (49 out of 129 = 38% of total unit patients). Two waves of TC (5-20 min/week for 10-12 weeks) were completed over 12 months in groups of 31 and 18 patients. Records were kept of total TC time, laboratory value changes, number of hemodialysis sessions completed, and TC activities. Primary outcome was annual patient satisfaction survey score pre- and post-TC. Data was analyzed by descriptive statistics, percent survey score difference, and qualitative patient comment summary. Results showed the mean unit patient satisfaction survey rose from 85% to 93%. 82% met or exceeded mean laboratory goals during the TC compared to 66% pre-TC. Greatest effect was seen for albumin and phosphorus control. Higher TC time resulted in qualitative survey comments relating to "feeling of belonging" and/or higher score on staff involvement in their care compared to pre-TC. TC may be an effective, low-cost support technique that can involve all members of the interdisciplinary team.

3. PSYCHOLOGICAL STATUS AND END-OF-LIFE DECISION MAKING CONFIDENCE IN SURROGATES OF DIALYSIS PATIENTS Bridgman, J.C., Ward, S.E., Lin, F.-C., Hanson, L.C., Hamilton, J., Hladik, G., Fine, J.P., Sun, S., Miles, M., & Song, M.K., UNC-Chapel Hill, NC, UW-Madison, WI, USA

The psychological status of surrogate decision makers and assessment of their own decision making abilities *before* engaging in end-of-life decision making has received little attention. The purpose of this descriptive study of 120 surrogates of dialysis patients was to examine relationships among surrogates' psychological variables, end-of-life decision making confidence, and sociodemographic characteristics using baseline data from a randomized controlled trial. Surrogates completed the Hospital Anxiety and Depression Scale, Post-Traumatic Symptoms Scale (PTSS)-10 and the 5-item End-of-Life Decision-Making Confidence Scale. The majority of the sample was African American (65.8%), female (69.2%), and living with patients (62.5%). Although mean scores of anxiety, depression, and PTSS for the sample were within normal ranges, 35% (n=42), 11.7% (n=14), and 5.8% (n=7) showed abnormal scores on the anxiety, depression, and PTSS, respectively. Surrogate's decision-making confidence was high (M=17.70 out of 20). Surrogates' sex, years of education, total annual income, and overall rating of relationship quality with patients were significantly associated with psychological status ( $r = .20-.35$ ,  $p < .05$ ). Decision making confidence was associated only with the quality of relationship with the patient ( $r = .33$ ,  $p < .001$ ).

In this sample, we found no significant relationship between surrogates' psychological status and decision-making confidence. Surrogates' decision-making confidence may reflect their perceived relationship quality with patients. The lack of relationships between the psychological status and decision making confidence in this sample warrants future studies.

2. VIDEO EDUCATION INCREASES PATIENT KNOWLEDGE ABOUT PHOSPHORUS CONTROL AND IS A PREFERRED FORM OF EDUCATION

Shaun Boyd<sup>1</sup>, T. Christopher Bond<sup>1</sup>, Tonya Zimmerman<sup>1</sup>, Kathy Parker<sup>1</sup>, Darlene Griffin<sup>1</sup>, Duane Dunn<sup>1</sup>

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Nephrology care teams have attempted to achieve optimal phosphorus levels in patients through many methods of patient education and clinical interventions. We assessed the acceptance of a video education program designed to inform hemodialysis patients about controlling their serum phosphorus levels and other dialysis-related topics.

The video education program was conducted in 20 centers in 1 division of a large dialysis provider's network. Patients completed questionnaires about their knowledge of phosphorus control and preferences regarding types of education (handout, video, one-on-one counseling, and group presentations) before and after the initiative. The video program consisted of 6 videos shown at 1-week intervals and covering the following topics: understanding kidney function and kidney disease treatment options, mineral and bone disorders, benefits of fistula use over catheter use, success stories (highlights of patients leading successful and happy lives while on dialysis), and 2 videos on cooking and making dialysis-friendly meals.

The 771 patients who completed both the pre- and post-test scored significantly better ( $p < 0.05$ ) on 5 of 7 knowledge components after the 6-part program than they had beforehand. In general, patients had a very positive response to video education, with 44% of patients ranking it higher than they had beforehand and only 23% ranking it lower. The percentage of patients who said video education was their most preferred method rose from 22% to 40%. Of the 936 patients who took the post-program test, 86% said the program improved their overall understanding of dialysis and 83% said they would like to see more video education in the future. The percentage of centers that ranked video education as the most preferred format overall rose from 20% to 65%.

The 6-week video education program improved patient knowledge of dialysis and was a well-accepted method of patient education.

4. HOW UNDERGRADUATE AND GRADUATE SOCIAL WORK STUDENTS CAN HELP LOCAL KIDNEY DISEASE COMMUNITIES: RECOMMENDATIONS FOR NEPHROLOGY PROFESSIONALS

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This research describes a project that trains 5 undergraduate and 3 graduate social work students in kidney disease and health disparities research. Working on this research project has strengthened the students' scholarly pursuits by helping them understand a myriad of barriers to community health (and kidney disease outcomes specifically) that are discussed in their classes. Possible roles and activities for students, and partnerships between academics and nephrology professionals, are discussed. These activities include research on kidney disease disparities, and learning about kidney disease to enhance the students' knowledge and appreciation of the public health crisis of kidney disease. In addition, these students have participated in a myriad of activities with the local National Kidney Foundation office, benefiting dialysis professionals, patients, the NKF, and the students. Suggestions for how dialysis professionals can take advantage of opportunities related to working with local universities and scholars are provided- this is a necessary step as few academics (particularly in social work) focus on kidney disease.

5. RECOMMENDATIONS FOR DIALYSIS TEAM MEMBERS TO HELP REDUCE KIDNEY TRANSPLANT DISPARITIES

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Research suggests that black dialysis patients are significantly less likely than their white peers to be evaluated and listed for a kidney transplant. We present the findings of two research studies that survey black dialysis patients in two different locations (Chicago and Philadelphia) about their attitudes and knowledge related to kidney transplantation, and use these findings to make recommendations to the interdisciplinary dialysis team members that may help reduce kidney transplant disparities. In the Chicago study, 94% of patients surveyed were interested in a kidney transplant, only 36% had been evaluated at a transplant center, and even less, 9% active on a transplant waiting list. Insurance was not a barrier, as 98% had insurance that would pay for a kidney transplant. In the Philadelphia study, the majority (80%) of patients were interested in a kidney transplant, (71.6%) had been evaluated, yet only 39% were on the transplant waiting list. Moreover, of the patients being evaluated 52.9% incorrectly believed they were on the kidney transplant waiting list. In the Chicago study the barrier was access to transplant, in the Philadelphia study patients had difficulty navigating the transplant system. In both studies, black patients had poor knowledge and understanding about the process related to getting a kidney transplant. These findings suggest that barriers to kidney transplantation are complex and multidimensional. Furthermore, dialysis professionals can augment their standard course of patient care to identify and attend to this lack of knowledge and understanding.

7. RESPONSE RATES TO THE KDQOL IN CHRONIC DIALYSIS PATIENTS.

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The Kidney Disease Quality of Life (KDQOL) survey is often administered to patients receiving chronic dialysis, although little is known about response rates in the community and reasons why patients decline the survey when administered outside of a clinical trial. We examined differences between dialysis patients who completed the KDQOL (responders) and those that did not (non-responders) as part of a quality assurance project. Four social workers from two chronic dialysis facilities offered the survey to patients as part of their routine care over a 12 month period. Data was analyzed with PASW v18.

Of the 133 patients offered the KDQOL, only 56.4% completed the survey. There was no difference in response rate by sex, age, race, or Medicaid status. Home dialysis patients were more likely to complete the KDQOL (OR 17.6, 95% CI 4.0-77,  $p < 0.0001$ ). Non-responders tended to have been receiving dialysis longer with a mean of 58.7 months, compared to responders at 41.8 months ( $p = 0.054$ ). Of the non-responders, 34.5% had previously completed a KDQOL survey in the facility. There was significant variability in response rate between the in-center hemodialysis social workers ranging from 21.8% to 61.5% (Chi-Square 10.7, df 2,  $p = 0.005$ ).

In summary, the KDQOL was more likely to be completed by home dialysis patients, and those that had been receiving dialysis for a shorter period of time. However, the approach used by the survey administrator impacts response rates and is a modifiable factor. Additional study is needed to determine why patients who previously completed the KDQOL refused to complete follow up surveys.

6. RESEARCH INTERESTS AND EXPERIENCE OF SOCIAL WORKERS WITHIN A LARGE DIALYSIS ORGANIZATION

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Nephrology social workers play a critical role in many aspects of ESRD patient care. The contributions of social workers to research are therefore important to the ESRD community however there is very little information in the literature relating to research participation and the research interests of nephrology social workers.

Social workers within a large dialysis organization were invited to complete a survey of research interests and participation. From 1300 social workers contacted, 601 responses were received, corresponding to a response rate of 46%. Eight percent of respondents indicated that they had participated in a research project within the last 5 years as part of a thesis project, with 11% indicating that they had participated in a research project outside of their thesis work. Those that had participated in research projects were involved in a variety of capacities (consultant, 19%; study coordinator, 23%; sub-investigator, 32%; principal investigator, 16%). Survey respondents identified lack of opportunity and lack of capacity as the primary barriers to participation in research. Medication adherence, modality education, and motivational interviewing relating to central venous catheter reduction efforts were identified as areas in which research would be most valuable.

The survey results give an indication of the current levels of participation in research by social workers and the potential barriers to involvement. The areas of research priority identified by social workers are well aligned with the needs of the ESRD community, and our results suggest that ESRD and dialysis organizations might consider developing models to provide opportunities and capacity for social workers to participate in research projects.

8. PATIENT CENTERED ADVANCE CARE PLANNING IN DIALYSIS: PHASE ONE

Shiloh D. Erdley, Ion D. Bucaloiu, Evan R. Norfolk, Martha Kitchen, Vonda Hetherington, Danville PA,

Due to the high mortality rates and significant symptom burden of dialysis patients, attention to advance care planning (ACP) has grown in the nephrology community. The optimal system for addressing ACP in dialysis units is not known. We report a quality initiative project utilizing a multidisciplinary ACP team, aiming to systematically and timely address ACP in the outpatient dialysis unit setting.

A team consisting of a nephrologist, renal social worker, unit registered nurse team leader and a renal dietitian, identified patients with advanced illness (defined as probability of survival at 18 months less than 80%) using an online prognostic calculator (<http://touchcalc.com/calculators/sq>). Patients were asked whether they had advanced directives (AD) and were provided with education regarding ACP. When AD was not available or not completed, patients were reminded to do so. During routine monthly interdisciplinary team meetings, members of the team reminded primary nephrologists to ask themselves whether they would be surprised if any of their patients would die in the next 6 months, and based on the answer, made recommendations regarding potential need for a referral to palliative medicine. AD completion, referrals to palliative medicine, number of hospitalizations prior to death, and referrals to hospice were noted.

AD completion rates in our unit increased from 21/67(31.3%) at baseline to 34/70 (48.5%) at 1 year. Of 67 prevalent patients 16 (23.8%) died during this time. 87.5% (14 of 16 deceased) were identified to have less than 80% predicted 18 months survival, a median (s.d.) of 97.5 (87.2) days prior to demise. In this group, AD completion increased from 5/14 (37.7%) to 11/14 (71.4%) at 1 year.



9. "MOVIN' ON UP": TRANSITIONING ADOLESCENT KIDNEY TRANSPLANT PATIENTS TO ADULT CARE

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Jill Macfarlane, Primary Children's Hospital, Salt Lake City, Utah, USA  
 The purpose of the "Movin' on Up" adolescent transition program is to prepare our pediatric patients to move into adult medical care. Clinical data suggests that young adults are at risk of losing their transplanted kidney during this transition phase. We have become increasingly aware that many of our pediatric patients were not well prepared to take on the responsibilities of their illness.

In order to prepare our patients for transition to adult nephrology, we developed a series of tasks designed to help the patient achieve the skills needed to meet the responsibilities of lifelong chronic illness. These tasks included education and testing on renal transplant care. The program is introduced to the patient and their parents at age 12. Medical and psychosocial education is introduced and reinforced with a series of worksheets and quizzes. Interdisciplinary teams including pediatric and adult physicians participate in the program.

Over the past year and one half, a group of patients have graduated from the program and transferred to adult care. Upon graduation, patients completed a survey and subjective responses indicated their readiness for independent care.

In conclusion, the Movin' On Up adolescent transition program provided teens with supportive education and skills development. The patients reported that this program prepared them for the responsibility of adult care.

11. COORDINATED INTERDISCIPLINARY PATIENT EDUCATION CALENDAR

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Patient education is an ongoing and integral part of the dialysis professionals' role in helping patients towards optimal outcomes through adherence to their treatment regime. This model demonstrates an educational plan used by Nursing, Dietary and Social Work where there is one monthly topic with focused contributions from each discipline. Uniquely the social work contribution is presented from a biopsychosocial model to successfully move the patient from knowing to doing. We focus on variables that influence engagement in healthy behaviors and adherence to medical regimens. Below is the 2012 calendar.

Jan	Coping with Dialysis	July	Access and Quality of Life
Feb	Treatment Options and Adherence	Aug	Exercise
Mar	Knowing your Healthcare Team Self Advocacy	Sept	Health Management at Home and Care Giver Support
April	Medical Complications Associated with Kidney Disease	Oct	Winter Preparation
May	Travel	Nov	Holiday Preparation
June	Fluid Management	Dec	Setting and Maintaining Your Goals

The development of a cross discipline plan allows the team to approach education utilizing multi-media including interactive lobby demonstrations, audio and visual media, hand-outs and bulletin board posting. These tools and team approach serves to increase participation and decrease communication barriers for pts with different learning needs.

10. EVALUATION OF A RENAL TEAM LEARNING MODULE ON WORKING WITH YOUNG ADULTS (YA) WITH CHRONIC KIDNEY FAILURE (CKF).

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In a recent Michigan multi-center study, it was shown that renal teams did not differentiate between their YA population and the rest of their older dialysis population. Given YA high rates of non-adherence, morbidity and mortality, several programs joined forces to equip renal teams to improve YA outcomes.

Pre- and post- surveys were developed to measure knowledge and confidence level of renal professionals in their work with this population to be administered via an educational power point presentation. The effectiveness of the teaching module, delivered to 70 renal staff, was evaluated at a state symposium in Michigan. The Michigan Department of Community Health IRB approved this initiative. Sixty-six participants completed the pre- and post-survey.

Knowledge increased post presentation, particularly regarding cognitive development in the YA. This teaching module positively influenced the confidence level regarding working with YA of several sub-groups. The decreased confidence of techs may reflect discomfort with the new information. These results indicate that there is a need for increased knowledge and confidence among renal professionals who work with YA with CKF. Future plans include presenting this module to a wider audience of renal staff. Seven attendees committed to offer this educational module as an in-service for their clinic personnel.

Attendees	N	Likert Scores	P Value	Confidence Δ in Working w/ YA
All	66	3.68 to 3.8	0.073	marginally significant
RN	26	3.65 to 3.88	<0.05	significant
RD	9	3.77 to 3.89	0.3	no change
SW	20	3.65 to 3.9	<0.05	significant
Tech	10	3.9 to 3.4	<0.05	Significant

12. KIDNEY DONATION & ANXIETY: COMPARISON BETWEEN COUNSELED & NON-COUNSELED KIDNEY DONORS

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Psychological evaluation of the kidney donors lays ground work for post transplant follow-up. It is noted that donors do face psychological problems especially when graft fails.

The present study is aimed at finding out the efficacy of counselling by measuring the anxiety. Kidney donors were divided into 2 groups (Counselled donors(C) n=30 and Non-Counselled donors (NC)n=30) during the three phases of kidney donation namely: At the time of registration, prior to kidney donation, six months after kidney donation.

Anxiety was assessed by Comprehensive Anxiety Test (CA Test) Sharma, Bharadwaj & Bhargav (1992). This 90 item inventory explores the factors responsible for anxiety, broadly into 3 categories i.e. biological, psychological & sociological correlates of anxiety.

CA score: Comparison between Counseled & Noncounseled kidney donors

**Table: 1**

**At the time of registration**

	n	Mean	SD	SEM	t	p
Counseled (C)	30	33.4	10.5	1.92	1.39	0.08
Non-counseled NC)	30	37.2	10.6	1.93		

**Table: 2**

**Prior to kidney donation operation**

	n	Mean	SD	SEM	t	p
Counseled (C)	30	30.1	10.2	1.86	2.72	0.004
Non-counseled NC)	30	37.2	10.1	1.84		

**Table: 3**

**Six months after kidney donation**

	n	Mean	SD	SEM	t	p
Counseled (C)	30	29.8	11.1	2.02	2.78	0.003
Non-counseled NC)	30	37.1	9.2	1.68		

The above results show that the 't' & 'p' values were significant prior to kidney donation & six months after kidney donation. Effective counselling helps reduce anxiety in kidney donors and better prepares them psychologically to face post-operative consequences.

13. MOTIVATIONAL INTERVIEWING STAFF TRAINING PROTOCOL REFINEMENT PROJECT

Leanne Peace, Cynthia Russell, Nikole Cronk, Michelle Matteson, Leonor Ponferrada, Norma Knowles, Kay Dye; University of Missouri-Columbia and Dialysis Clinics Inc, Columbia Missouri.

Motivational Interviewing (MI) has been well-documented as an effective tool for facilitating health-related behavior change among chronically ill patients. The initial research was to determine if MI conducted by staff improved patient adherence. Adequate staff training is paramount for effective delivery of MI. The purpose of this project was to develop and refine an MI hemodialysis staff training protocol. In the initial phase of this project, dialysis staff received a 9 hour MI training program (three, 3-hour sessions) followed by 2 months of coaching and counseling by an MI specialist. The staff then delivered MI to hemodialysis patients for 3 months. Staff evaluation of this training approach indicated that the concepts of MI were easy to understand, appropriate, and likeable, but they were not used regularly or effectively. Staff felt that they needed a longer training session with additional coaching and counseling.

Consequently, the MI delivery methods were refined for phase II. The revised protocol included a longer staff training session (four, 3 hour sessions with additional time between sessions 3 and 4 for reinforcement), more coaching, along with more frequent counseling sessions and extension of the MI delivery phase to 6 months. For continuity and consistency, a single MI expert provided the training and coaching sessions in both phases.

This project has produced a much needed protocol for training hemodialysis staff on the effective use of MI. Study protocol revisions indicates that sufficient MI training, feedback and follow up coaching may enhance MI competence and comfort in using the technique for long term use. Similar MI training protocols may be adapted for use by other facilities to improve patient and staff interactions.

15. EVALUATION OF TRANSPLANT EDUCATION IN 500 DIALYSIS CENTERS IN 21 STATES: ARE DIALYSIS PATIENTS MAKING INFORMED TREATMENT CHOICES?

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Dialysis centers are mandated by the Centers for Medicare and Medicaid Services to provide evidence that patients are informed of their transplant options. The purpose of this study was to understand the specific transplant education practices commonly occurring in dialysis centers nationwide. We surveyed 509 dialysis providers responsible for transplant education for approximately 32,000 patients in 551 dialysis centers serving 21 states. Transplant educators were primarily social workers (33%), nurses (32%), nurse managers/facility administrators (19%) and dialysis technicians (11%) who had been working with dialysis patients, on average, for 12 years. Though 92% agreed that educating patients about transplant was a priority (25% somewhat agreed, 67% strongly agreed), only 33% had a formal transplant education program in operation in their dialysis centers. Providers had poor knowledge about transplant (answering 6 of 12 general transplant knowledge questions incorrectly). Educators admitted that their transplant knowledge was inadequate for answering their patients' questions (53%) and felt their transplant education materials were poor (39%). When asked about their specific educational practices, most (93%) provided patient education at least once to all transplant-eligible patients, with less (78%) repeating this education every year. Their education primarily consisted of recommending that patients be evaluated for transplant (84%), recommending that patients learn more about transplant (80%), and referring patients to an education program at a transplant center or kidney organization (59%). Educators rarely had detailed discussions about the risks and benefits of deceased (25%) or living donation (25%). While dialysis educators are generally informing patients that the option of transplant exists, few are providing patients with true transplant education. To enable more dialysis patients to make informed transplant choices, we must educate more dialysis providers about transplant and provide them with adequate transplant resources to disseminate to patients.

14. PERCEPTIONS AND ROLES OF THE NEPHROLOGY SOCIAL WORKER WITHIN THE SUICIDE CONTINUUM OF CARE: A NATIONAL SURVEY

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The Nephrology Social Worker (NSW) is relied upon when patients present with suicidal ideation (SI) and other mental (MH) health concerns within the dialysis setting. A 20-question Survey Monkey instrument, with some multiple component questions, was presented to all participants in the Council of Nephrology Social Workers listserv and to all DaVita social workers. The questions addressed roles assumed within the dialysis clinic, available resources, NSW confidence and skill level in assessment, and intervention within the continuum of SI-plan-attempt. Knowledge of physical and MH conditions that contribute to patient SI was also investigated.

Statistical Package for the Social Sciences software was utilized to analyze data of 528 respondents from 46 states and 2 territories. Findings include: 60% of NSWs surveyed were licensed; 39% were in practice for 16 or more years; 50% work in only 1 clinic (range 1-5); and being respected by coworkers demonstrates the highest component within job-satisfaction questions. NSWs' self-perceptions included being a value to their organization, being the "go to" person in MH crisis management above and beyond all others within the patients' care system. NSWs interact with patients wanting to die without mention of suicide; and NSWs identified working with patients who have SI with or without a plan. Greater numbers of NSWs report care to patients who have attempted suicide than have received MH care. At or beyond the 6<sup>th</sup> year, NSWs' knowledge and skills are crystallized in identifying and intervening when patients have SI/ideation with a plan. The gaps in NSWs' level of understanding and confidence varied by years of service.

NSWs are the experts on suicidal and MH issues within the dialysis clinic. Data suggest the NSWs' knowledge, skills, and confidence vary within the years of service. Training for newly hired NSWs and those serving within internship settings is indicated. Best practice knowledge is identified and a significant knowledge gap is likely.

16. PREEMPTIVE TRANSPLANT KNOWLEDGE AND DECISION-MAKING: IMPACT OF A COMMUNITY CKD EDUCATION CLASS

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Patients who can get a preemptive living donor transplant (PLDT) avoid medical complications related to dialysis and have the highest graft success and lowest patient mortality rates. Limited research is available to understand how PLDT education affects patients' transplant coping, knowledge, and behavior. The Missouri Kidney Program's community Patient Education Program (PEP) educates patients not yet in kidney failure about their transplant and dialysis options. From September, 2008 to May, 2010, we surveyed 352 patients (78% White; 93% not on dialysis), before and after 36 PEP classes to assess changes in their transplant knowledge, pro-transplant attitudes, confidence, and interest in PLDT. Fifteen months later, we assessed their pursuit and receipt of PLDTs using SRTR data. Pre-class, only 15% of patients had spoken to a transplant coordinator, 8% had been evaluated for a transplant and 4% reported they were on the transplant waiting list. Post-class, patients had greater preemptive transplant knowledge (51% vs. 84% correct, p<.001), greater perceived benefits to transplant (5.5 vs. 5.0, p<.001), reduced fears about transplant (9.9 vs. 10.6, p<.001), and greater transplant confidence (7.2 vs. 6.4, p<.001). Post-class, 54% planned to be evaluated for a transplant. Fifteen months later, 78 patients (22% were either actively pursuing or had received a deceased or living donor transplant (12 PLDTs, 3.4% of attendees). A community education program can educate and motivate patients who are not yet in kidney failure to make informed transplant decisions and consider the option of PLDT.



