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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

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

The Council of Nephrology Social Workers of the National Kidney Foundation, Inc.

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ISSN 1532-0863

The Journal of Nephrology Social Work is published by the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Professional membership in the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. ($65.00 annually domestic and $70.00 international) includes subscriptions to *The Journal of Nephrology Social Work, Renalink* and selected materials as they are published by the National Kidney Foundation, Inc. Further membership information is available from the National Kidney Foundation at 800-622-9010 or from the CNSW Web site at **www.kidney.org** or by contacting CNSW Publications Chairperson, Norma Knowles, MSW, LCSW, Dialysis Clinic, Inc., 3300 Lemone Industrial Boulevard, Columbia, MO 65201-8246.

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.

If you are interested in becoming a member of the Editorial Board, please contact the publications chair
Norma Knowles, LCSW, Dialysis Clinics Inc., 3300 Lemone Industrial Boulevard, Columbia, MO 65201-8246.
E-mail: **Norma.Knwles@dciinc.org**

CALL FOR MANUSCRIPTS

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

- The Family
- Ethical Issues
- "How to" articles (ones which detail the development and implementation of innovative approaches to new and old psychosocial problems)
- Rehabilitation
- Group Work
- Sexuality
- AIDS and the Renal Patient
- The Use of Quality of Life Measurement Instruments for ESRD Patients
- Social Work Interventions and Outcomes

Articles should be mailed to: ***Jared Sparks,Tulane University School of Social Work, New Orleans, LA 70118. E-mail: jsparks2@tulane.edu***

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 six to 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 on the manuscript.

TYPES OF ARTICLES BEING SOUGHT

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

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

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

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

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

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

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

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

MANUSCRIPT SUBMISSION

Manuscript Format

Manuscripts should be formatted according to the rules laid out by *Publication Manual of the American Psychological Association*, *5th Edition*. What follows is a brief synopsis of the broader style points used by the APA.

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

Order of the Manuscript Sections

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

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

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

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

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

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

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

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

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*.

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

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

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

Figure 1. Exemplary formatting for all figure captions.

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

Reference Examples

Journal Article, Two Authors

Wassner, S. J. & Holliday, M. A. (1989). Protein metabolism in chronic renal failure. *Semin 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. J*ournal of Psychology and Theology, 19*, 6-25.

Journal Article, More Than Six Authors

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

Journal Article in Press

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

Complete Book, Edited

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

Chapter of an Edited Book

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

Article from a Journal Supplement

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

Abstract

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

Editorial

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

REVIEW PROCESS

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

AFTER ACCEPTANCE

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

- An electronic copy of the final version of the manuscript. All components of the manuscript must appear within a single word processing file, in the order listed above. 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.
- Individual files for each image, black and white (grayscale) only. Formatted as a TIFF or an EPS. 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.
- We would prefer a printed copy of the final version of the manuscript to be sent to verify contents.
- A copyright form signed by at least one of the authors.

**THE JOURNAL OF
NEPHROLOGY SOCIAL WORK**

Volume 25
May 2006

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A MESSAGE FROM THE EDITORS

I’m pleased to announce that the *Journal of Nephrology Social Work (JNSW)* is indexed in several bibliographic databases. To date, *JNSW* can be found in Social Work Abstracts, which indexes over 400 journals; Social Services Abstracts, which indexes over 1,300 journals; as well as CINAHL, an allied health information database, which indexes over 900 journals.

These databases are generally accessible through university libraries and some medical centers. This means that social workers, social work students, allied health professionals, and others interested in nephrology social work can identify articles in *JNSW* relevant to their search inquiry.

Since *JNSW* is a title not currently physically held by many libraries, we are exploring the possibility of being available in full text databases within these indexing services. There is also a possibility that *JNSW* may be faxed or mailed through some of these services. To be included in PsychINFO we need to have articles written in APA format with an abstract and author affiliations. The more research articles generated the better. With that said, we also invite and value any contribution that nephrology social workers may have including editorials and reviews.

A heartfelt thank you to all who have made this journal and its growing success possible.

Sincerely,

Jared Sparks, LCSW-BACS, DCSW,
Co-Editor-in-Chief

National Kidney Foundation
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THE COUNCIL OF NEPHROLOGY SOCIAL WORKERS

LITERATURE REVIEW: Nephrology Social Work: History in the Making

Teri Browne, MSW, LSW, Fresenius Medical Care North Avenue Dialysis, Melrose Park, IL;
Chairperson, NKF Council of Nephrology Social Work

This literature review also includes content written over the years by the Council of Nephrology Social Workers.

January 28, 2005 was a landmark day for the nephrology community, as it was the day that the Draft Conditions for Coverage (COC) for End Stage Renal Disease (ESRD) Facilities were released by Medicare. These are the regulations that dictate policies and procedures in all dialysis and transplant facilities. This occasion is a landmark for a few reasons. Foremost, this document is what sets nephrology social workers apart from social workers in any other medical setting—it dictates that every dialysis and kidney transplant center must have a master's-level social worker on its interdisciplinary medical team. This is very unique to the nephrology field only, and is the sole Medicare provision of its kind that recognizes that an illness like CKD carries with it such psychosocial issues that only a master's-level social worker can competently address with patients and their families.

This date is also notable because it is very rare—there have not been significant changes in these conditions since the 1970s. As the title of this article implies, nephrology social work history is being made with the revision of these conditions, as they will set the policies for patient care for the foreseeable future. This article briefly reviews the Council of Nephrology Social Work (CNSW) response to the conditions, and provides a compilation of empirical data used to create CNSW's position papers to the COC.

CNSW'S RESPONSE TO THE COC

CNSW (along with the other NKF professional councils) had been waiting for these draft conditions to be released for almost a decade, and had an anticipatory response ready to go as soon as they came out. CNSW Membership Chair, Rita-An Kiely, kept in close touch with CMS and was the first to “break the news” that the draft conditions were available. This was followed by a whirlwind of CNSW membership and Executive Committee listserv activity; the creation of the Executive Committee's “suggestions for comments” for members to use to draft their own responses; the creation of a CNSW official response to the dialysis and transplant COCs (many elements of which were used in the National Kidney Foundation's position paper about the COC); and encouragement of all members to make their voices heard about this document. This went as far as having 44 social workers attending the NKF 2005 Spring Clinical Meetings, who had not yet sent in their responses, go to a social worker's hotel room at the meetings and submit a response before the deadline. Ultimately, many social workers contributed suggestions about the COC. The final revisions are not due until a few years from now, at which point they will become the policies and procedures in all dialysis and transplant facilities.

A COMPILATION OF RESEARCH USED TO CREATE THE CNSW RESPONSE

Recognizing that individual responses were strengthened by the use of empirical data to support member opinions, an exhaustive literature review was conducted, itemized and distributed to the CNSW membership for use in creating individual responses to the COC. This review includes a summary of research about: general psychosocial ramifications of CKD and its treatment regimes; unique psychosocial needs of pedicatric and older patients; psychosocial influence of comorbid issues common with ESRD; as well as psychosocial issues common in ESRD, such as: sexuality and fertility issues, functional status, economic concerns, quality of life, families and support networks, anxiety, depression, rehabilitation, transplantation specific issues, sleeping problems, body image concerns, failed transplant, nonadherence to treatment regime, end-of-life issues, suicide and the ramifications of psychosocial issues related to ESRD.

The review then summarizes evidence of the efficacy of nephrology social work interventions including: CNSW background material; why nephrology social work interventions are recommended; why CKD multidisciplinary team care (including an MSW) is recommended; nephrology social work assessment considerations; why social workers have been shown to be an important part of the transplant team; support for appropriate nephrology social work tasks and evidence of misutilization of master's-level social workers; support for nephrology social worker/patient ratios; and CNSW support for master's-level social workers service provision.

PSYCHOSOCIAL RAMIFICATIONS OF CKD AND ITS TREATMENT REGIMES

General Information

End Stage Renal Disease (ESRD) is a chronic illness that requires lifestyle changes and accommodation that affect all spheres of living: medical, dietary, social, financial, psychological and rehabilitative. The lifetime course of the ESRD patient's treatment may include multiple renal transplants and different treatment modalities; vascular and peritoneal access problems; life-threatening infections; amputations; severe bone disease; family dysfunction; changes in functional status and issues of palliative care; and dying. 89% of ESRD patients reported that the disease caused many changes in their lifestyles (Kaitelidou, Maniadakis, Liaropouls, Ziroyanis, Theodorou & Siskou, 2005). The chronicity of ESRD and the intrusiveness of required treatment provide renal patients with multiple psychosocial stressors including: cognitive losses, social isolation, bereavement, coping with chronic illness, concern about mortality and morbidity, depression, anxiety, psycho-organic disorders, somatic symptoms, lifestyle disruption attributable to intrusive treatment regime and schedule (length, frequency), economic pressures, insurance and prescription issues, employment and rehabilitation barriers, mood changes, body image issues, concerns about pain, numerous losses (income, financial security, health, libido, strength, independence, mobility, schedule flexibility, sleep, appetite and freedom with diet and fluid), social role disturbance (familial, social and vocational), dependency issues, and diminished quality of life (DeOreo, 1997; Gudes, 1995; Katon & Schulberg, 1997; Kimmel et al., 2000; Levenson, 1991; Mapes, 1991; Rabin, 1983; Rosen, 1999; Soskolne & Kaplan-DeNour, 1989; Vourlekis & Rivera-Mizoni, 1997).

Unique Psychosocial Needs of Pediatric Patients

Children and adolescents with ESRD may be especially concerned about body image issues related to required vascular accesses (Fielding, Moore, Dewey, Ashley, McKendrick, & Pinkerton 1985). 59% of ESRD adolescents had poor adherence with recommended medical regime (Kurtin, Landgraf, & Abetz, 1994). Infants born with ESRD require frequent hospitalization and medical appointments, have diminished development, may need supplemental nourishment or a feeding tube, and are usually precluded from transplant their first two years (Brady & Lawry, 2000).

Unique Psychosocial Needs of Older Patients

The demographics of the renal patient population have drastically changed, from younger heads of families to an increasingly high percentage of elderly patients with numerous co-morbidities and social problems. Individuals 65 years and older, with numerous additional co-morbidities and social problems, comprise the fastest-increasing population among ESRD patients (Kutner, 1994; Mold & Holt, 1993). Older adults with ESRD have more somatic complaints (Chen, Wu, Wang, & Jaw, 2003).

Psychosocial Influence of Comorbid Issues Common with ESRD

ESRD is often secondary to chronic illnesses such as hypertension and diabetes, which provide ESRD patients with additional psychosocial issues, and predispose the ESRD patient to frequently access health services from many community providers (Merighi & Ehlbrecht, 2004). Low albumin and co-morbidities in ESRD patients can independently decrease patient quality of life (QOL) (Frank, Auslander & Weissgarten, 2003). Coronary artery disease in menopausal women with chronic kidney disease (CKD) is associated with cognitive impairment (Kurella, Yaffe, Shlipak, Wenger, & Chertow, 2005). Diabetic ESRD patients have higher depression scores and affective change scores than those without diabetes (Chen, Wu, Wang, & Jaw, 2003). ESRD patients commonly have pain, which is very intrusive and decreases quality of life (Devins et al. 1990). Anemia is common in ESRD patients, which prohibits activities of daily living, diminishes quality of life, decreases energy, and increases fatigue (Schatell & Witten, 2004). Anemia is associated with lower quality of life in CKD adolescents (Gerson et al. 2004). Restless leg syndrome is common in ESRD patients, which is significantly related to increased anxiety (Takaki, et al. 2003).

Psychosocial Issues Related to ESRD: Sexuality and Fertility Issues

Sexual functioning may be diminished due to ESRD, comorbidities and medication regimes, and are found to be very important concerns for dialysis patients (Wu et al., 2001). ESRD female patients have a low fertility rate due to their abnormal reproductive endocrine function and numerous pregnancy complications. Women on daily home hemodialysis may be more likely to have successful pregnancies (Holley & Reddy, 2003).

Psychosocial Issues Related to ESRD: Functional Status and Economic Concerns

ESRD patients have a lower functional status than the general population and are likely to need assistance with activities of daily living (Dobrof, Dolinko, Lichtiger, Uribarri & Epstein, 2000; Kimmel, 2000). ESRD can lead to financial loss, which is a very important concern for patients (Wu et al., 2001).

Psychosocial Issues Related to ESRD: Quality of Life

ESRD commonly results in diminished patient quality of life (Frank, Auslander & Weissgarten, 2003; House, 1987; Kimmel, 2000). Social workers can intervene to improve ESRD patient quality of life and address psychosocial issues impacting it. Poor quality of life in ESRD is significantly linked to patient outcomes: decreased functional status, decreased well-being, increased hospitalizations, increased morbidity and higher mortality (quality of life has been found to be as important a mortality marker as albumin level) (DeOreo, 1997; Kutner, 1994; Mapes, 2004; McClellan, Anson, Birkeli, & Tuttle, 1991; Parkerson, Broadhead, & Tse, 1995). Psychosocial status may be more important than physical status in predicting ESRD patient quality of life (*Promoting Excellence in End-of-Life Care*, 2002).

Psychosocial Issues of Patients' Families and Support Networks

ESRD has significant psychosocial ramifications for patients' families and social support networks, and social support can have influence on ESRD outcomes. Social workers can assist patients' support networks in coping with the stress and losses resulting from ESRD, and assist in helping patients build social support, which can lead to better patient outcomes (Kimmel, 1990; Benik, Chowanec, & Devins, 1990). Patients' spouses and partners cope with role reversal and more responsibilities (Gudex, 1995). 51% of ESRD family members reported absences from work related to the patient's illness (Kaitelidou, Maniadakis, Liaropouls, Ziroyanis, Theodorou & Siskou, 2005). Parents of pediatric ESRD patients have financial burdens and may be unable to work due to the illness and treatment regime (Brady & Lawry, 2000; Nicholas, 1999). Parents of pediatric ESRD patients are more likely to have anxiety, depression, and coping problems (Fukunishi & Honda, 1995). Families of ESRD patients are insufficiently knowledgeable about the illness and its trajectories, medical complications and comorbidities, treatment options and their impact on lifestyles (MacDonald, 1995). ESRD patients' family members have increased stress and coping issues (Pelletier-Hibbert & Sohi, 2001). Positive social support, particularly from the patient's family, has been found to be related to better patient outcomes, including improved adherence to the treatment regime, lower levels of depression, increased activity levels, improved psychological well-being, and morbidity and mortality (Burton, Kline, Lindsay, & Heidenheim, 1986; Cohen & Syme, 1985; Kimmel et al., 2000; Kutner, 1990; McClellan, Stanwyck, & Anson, 1993). It has been shown that dialysis patients' partners experience significant concern and coping issues regarding ESRD and treatment modalities in addition to the patient (Nichols & Springford, 1984; White & Greyner, 1999).

Psychosocial Issues Related to ESRD: Depression

ESRD can result in patient anxiety. 52% of patients have been found to have anxiety (Auslander, Dobrof, & Epstein, 2001; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000). Depression is very common in ESRD. ESRD patients are more likely to be depressed than the general population, with depression incidence as high as 49% (Auslander, Dobrof, & Epstein, 2001; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000; Finkelstein & Finkelstein, 1999; Hedayati et al., 2004; Wuerth, Finkelstein, Ciarcia, Peterson, Kliger, & Finkelstein, 2001). Depression is a serious problem in ESRD patients.

Depression is significantly related to malnutrition and poor nutritional outcomes (Kimmel, et al., 2000; Koo et al., 2003).

Depression has been found to be independently linked to ESRD patient mortality (Hedayati et al., 2004; Kimmel et al., 2000; Paniagua, Amato, Vonesh, Guo, & Mujais, 2005; Shulman, Price, & Spinelli, 1989).

Depression is linked to greater hospitalizations of ESRD patients (Paniagua, Amato, Vonesh, Guo, & Mujais, 2005).

Depressed CAPD patients have greater incidence of peritonitis (Wuerth et al, 1997).

Depression can diminish ESRD patient quality of life (Kalantar-Zadeh, Kopple, Block, & Humphreys, 2001; Mollaoglu, 2004). This is important because poor quality of life in ESRD is significantly linked to patient outcomes: decreased functional status, decreased well-being; increased hospitalizations; increased morbidity and higher mortality (DeOreo, 1997; Kutner, 1994; Mapes, 2004; McClellan, Anson, Birkeli, & Tuttle, 1991; Parkerson, Broadhead, & Tse, 1995).

Psychosocial Issues Related to ESRD: Rehabilitation

ESRD can have a significant impact on patients' rehabilitation status due to diminished physical status and intrusive treatment schedule issues. Social workers can assist patients in maximizing their rehabilitative status. One study found that only 13% of ESRD patients were able to resume employment after starting dialysis (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000). Kaitelidou, Maniadakis, Liaropouls, Ziroyanis, Theodorou, & Siskou (2005) found in a study of Greek patients that 60% of hemodialysis patients had to change professions or retire due to treatment requirements; only 40% kept their original profession; 7% of agricultural and 6% of blue collar workers kept the same profession; 55% of white-collar workers were able to keep their jobs; 37% retired before the official retirement age; 64% had absences from work; 39% reported working with ESRD symptoms an average of five days per month on which they were 62% productive. Working patients have been found to be more likely to miss a dialysis treatment (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000). Working patients have been found to be less depressed (Chen, Wu, Wang, & Jaw, 2003). Patients with the best rehabilitation status have a better quality of life (Mollaoglu, 2004). Low activity levels in ESRD patients are related to higher mortality (Husebye, Westle, Styrvoky, & Kjellstrand, 1987).

Psychosocial Issues Related to ESRD: Transplantation-Specific

Psychosocial factors such as finances, depression, relationship changes and employment lead to transplant immunosuppressant noncompliance (Russell & Ashbaugh, 2004). It has been demonstrated that kidney transplant patients, compared to dialysis patients, have overall improved physical and mental health, lower mortality, greater social functioning and enhanced quality of life (Dew, Goycoolea, Switzer, and Allen, 2000; Evans et al. 1985; Gokal, 1993; Simmons and Abress, 1990). ESRD patients may have significant difficulty transitioning from dialysis patient to transplant patient (due to uncertainty, unpredictability, redesigning goals) (Levine, 1999).

Psychosocial Issues Related to ESRD: Sleeping Problems and Body Image Concerns

ESRD patients often have sleeping problems (Valdez, 1997). ESRD patients have body image issues related to vascular and peritoneal access and medication side effects (especially immunosuppressants) (Beer, 1995; Sloan & Rice, 2000).

Psychosocial Issues Related to ESRD: Nonadherence to Treatment Regime

Nonadherence to the hemodialysis treatment schedule has significant ramifications for patients. Missing treatments and high interdialytic weight gains are associated with increased mortality (Husebye, Westle, Styrvoky, & Kjellstrand, 1987; Saran, 2003). In one study, 27-31% of patients missed one dialysis treatment per month; 35-41% signed off of dialysis early; 76-85% of patients had problems with diet; 75% of patients who were coping poorly were likely to miss treatments; 50% of patients who were coping poorly were not adherent with fluid gains (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000). 30-60% of dialysis patients do not adhere to recommended diet, medication or fluid recommendations (Bame, Peterson, & Wray, 1993; Friend, Hatchett, Schneider, & Wadhwa, 1997; Christensen & Raichle, 2002).

Psychosocial Issues Related to ESRD: End-of-Life Issues

Two percent of patients had marked psychosocial problems and concerns prior to their death (Woods et al., 1999).

Psychosocial Issues Related to ESRD: Suicide

It has been found that ESRD patients may be significantly more likely to commit suicide than persons in the general population (Kurella, Kimmel, Young, & Chertow, 2005).

Ramifications of Psychosocial Issues Related to ESRD

ESRD patients with a poor psychological status are more likely to be nonadherent to the treatment regime, have greater hospitalizations and higher mortality rates (DeOrea, 1997). ESRD patients who feel they are more in control of their treatment tend to cope better, be better adjusted and have better quality of life (Mapes, 1991; Bremer, 1995). ESRD patients with psychosocial problems and less understanding of the illness and treatment regime are more likely to have high interdialytic weight gains, and missed treatments. Patient psychosocial strengths, backgrounds and problems are related to dialysis outcomes (Auslander, Dobrof, & Epstein, 2001). Psychosocial issues (social support levels, adherence to dialysis regime, coping) related to ESRD are as important as medical issues in association with increased mortality (Kimmel et al., 1998). ESRD patient function status, depression, quality of life and activity level influence treatment regime outcomes, including morbidity and mortality (Burton, Kline, Lindsay, & Heidenheim, 1986; Gutman, 1983; Port, 1990). Serum albumin is accepted as a predictor of mortality (Lowrie & Lew, 1990). Many psychosocial risk factors (such as socioeconomic status, need for dentures, assistance needed to purchase groceries, decreased appetite due to depression or anxiety, decreased cognitive capability, management of diet, education, literacy, ethnicity, culture, household composition, insurance and social supports) can negatively contribute to albumin management (Calkins, 1993; Ellstrom-Calder & Banning, 1992; Oldenburg, Macdonald, & Perkins, 1988; Vourlekis & Rivera-Mizzoni, 1997). ESRD treatment outcomes are significantly impacted by a patient's psychosocial status (Burrows-Hudson, 1995; Burton, Kline, Lindsay, & Heidenheim, 1986).

EVIDENCE OF EFFICACY OF NEPHROLOGY SOCIAL WORK INTERVENTIONS

CNSW Background Material

ESRD patients require comprehensive psychosocial interventions at various stages throughout the course of their illness due to the multiple losses and psychosocial risks associated with their diagnosis and treatment. Socioeconomic and biopsychosocial barriers exist that negatively impact patient treatment outcomes such as morbidity and mortality. The identification of these barriers through a skilled biopsychosocial assessment is critical to maximizing patient outcomes. Providing skilled psychosocial interventions based on this assessment can ameliorate biopsychosocial risk factors, thus improving treatment outcomes for the ESRD patient.

The recognized role of the nephrology social worker is to: provide initial and continuous patient evaluation and assessment, including patients' social, psychological, financial, cultural and environmental barriers to coping with ESRD and their treatment regime; provide patients and their support networks with emotional support, encouragement and supportive counseling; provide assistance with adjustment to and coping with CKD, comorbidities and treatment regimes; patient and family education; crisis intervention; provision of information and community referrals; assistance with advance directives and self-determination issues; facilitate group work, including support groups and patient advocacy groups; case management with community resources, state agencies and federal programs; assisting patients with obtaining maximum rehabilitative status (including: ongoing assessment of barriers to patient goals of rehabilitation; providing patients with education and encouragement regarding rehabilitation; providing case management with local or state vocational rehabilitation agencies); providing staff in-service education regarding ESRD psychosocial issues; participate in the facility's quality assurance program; mediate conflicts between patients, families and staff; participate in interdisciplinary care planning and collaboration; and patient advocacy (Beder, 1999; Beer, 1995; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2001; Fortner-Frazier, 1981; Kimmel et al. 1995; McKinley & Callahan, 1998; McKinley, Schrag, & Dobrof, 2000; Merighi & Ehlebracht, 2004c; Nichols & Springford, 1984; Oldenburg, Macdonald, & Perkins, 1988; Petrie, 1989; Russo, 2002). The scope of these tasks is congruent with those traditionally related to medical social work in the realms of prevention, palliation, treatment and advocacy efforts directed at making health care more patient-centered (Dhooper, 1994).

Due to the complex nature of the renal patient's needs and issues, interdisciplinary collaboration of care for renal patients by the team has been found to be necessary for optimal delivery of services. A multidisciplinary approach (including a master's-level social worker) to CKD care has been shown to be effective in improving patient outcomes, and is the recommended method of providing CKD patient care (Corsini & Hoffman, 1996, Dunn & Janata, 1987; Gitlin, Lyons, & Kolodner, 1994; Goldstein, Yassa, Dacouris, & McFarlane, 2004; Houle, Cyphert, & Boggs, 1987; Warady, Alexander, Watkins, Kohaut, & Harmon, 1999). The severe psychosocial issues facing ESRD patients necessitate master's-level social work interventions, and research has shown that these interventions are vital to ameliorate the psychosocial barriers to ESRD treatment regime.

It is recommended that "a good psychosocial support program should be incorporated into the treatment of patients with chronic renal failure to reduce the possibility and severity of depression" (Chen, Wu, Wang & Jaw, 2003, p. 124). Research indicates that a decrease in depression correlates positively to increased adherence to the ESRD treatment regime which has a direct impact on decreasing morbidity and mortality (DeOreo, 1997). 76% of depressed dialysis patients indicate that they prefer to seek counseling from the nephrology social worker on their treatment team, rather than pursue care from an outside mental health practitioner (Johnstone & LeSage, 1998). Nephrology social work has been shown to effectively lower patient depression (Beder, 1999; Estrada & Hunt, 1998).

Renal social workers are the “natural source of health policy information for patients as well as other professionals” (Berkman et al. 1990), and they provide information to patients and their families about sources of information that are unknown to the family (Berkman et al; McKinley and Callahan, 1998). Arthur, Zalemski, Giermek, & Lamb (2000) have shown that nonrenal medical professionals (such as home care or nursing home care providers) are mostly unfamiliar with the psychosocial issues attributable to ESRD, such as patient eligibility for Medicare, patient ability to work and travel, patient self determination issues involving discontinuing treatment, and patients' sexual and reproductive problems. Renal social workers are key in assisting patients in navigating the service provision of their multiple medical needs, and advocating for patients with such community providers that are not attuned to such special needs.

Nephrology social work interventions have been shown to successfully: enhance/facilitate social support networks of patients and their families (Brady & Lawry, 2000; Johnstone, 2003; Spira, 1996); help patients and their families cope with ESRD and the treatment regime (Brady & Lawry, 2000; Frank, Auslander, & Weissgarten, 2003); help patients improve dialysis adequacy (Callahan, Moncrief, Wittman, & Maceda, 1998); help improve patient outcomes, including anemia status (Spira, 1996; Vourlekis & Rivera-Mizzoni, 1997); and help patients minimize nonadherence to ESRD treatment regime (Beder, Mason, Johnstone, Callahan, & LeSage, 2003; Callahan, Moncrief, Wittman, & Maceda, 1998; Johnstone, 2003). Social work education and counseling have been shown to reduce missed patient treatments by 50% (Medical Education Institute, 2004).

Social work intervention have also been shown to successfully: help patients reduce their interdialytic weight gains between dialysis treatments (Auslander & Buchs, 2002; Root, 2005). Clinical social work intervention was found to: be responsible for up to a 48% improvement in fluid adherence (Johnstone & Halshaw, 2003); improve ESRD patients' blood pressure (Beder, Mason, Johnstone, Callahan, & LeSage, 2003); increase ESRD patients' medication compliance (Beder, Mason, Johnstone, Callahan, & LeSage, 2003); reduce anxiety in CKD patients (Iacono, 2005; Sikon, 2000); improve ESRD patient quality of life (Callahan, Moncrief, Wittman, & Maceda, 1998; Chang, Winsett, Gaber, & Hathaway, 2004; Christensen, Smith, Turner, Holman, Gregory, & Rich, 1992; Frank, Auslander, & Weissgarten, 2003; Fukunishi, 1990; Johnstone, 2003; MacKinnon & MacRae, 1996; Sloan & Rice, 2000; Spira, 1996); improve patient activity level and rehabilitation status (Beder, Mason, Johnstone, Callahan, & LeSage, 2003; Callahan, Moncrief, Wittman, & Maceda, 1998; Ericson & Riordan, 1993; Institute on Rehabilitation Issues, 2001; Raiz, 1999); decrease patient morbidity and mortality via: increasing dietary adherence, enhancing patient coping and adaptation to ESRD and its treatment regimes, decreasing depression, increasing ESRD patient satisfaction and increasing patients' rehabilitation potential (Cummings, Kirscht, & Levin, 1981; Erickson, LeSage, Johnstone, & Parsonnet, 1991; Evans, 1990; Korniewicz & O'Brien, 1994; Lenart, 1998; LeSage, 1998; Parsonnet, 1991); reduce patient hospitalizations and emergency room visits (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000); improve patient adherence; improve functional status; assist the patient and family in coping with and adapting to changes brought about by ESRD and its treatment regimes (Berkman, Bonander, Rutchik, Silverman, Marcus, & Isaacson-Rubinger, 1990; Parsonnet 1991); and mediate conflicts in dialysis settings (Johnstone, Seamon, Halshaw, Molinair, & Longknife, 1997). Social work intervention and education increase advance directives completion by 51% (Yusack, 1999). Social work assessment and counseling can encourage patients to get a kidney transplant (Rosen, 2002) and may decrease racial disparity in transplantation (Wolfe, 2003 & Wolfe & Toomey, 2004). Psychosocial education and support can help patients stay employed and reduce hospitalizations that may inhibit employment (Raiz, 1996, Grumke & King, 1994, Rasgon, Schwankovsky, James-Rogers, Widrow, Glick, & Butts, 1993). ESRD psychosocial services enhance coping, encourage patient participation in their care and increase adherence (McKinley & Callahan, 1998).

Nephrology Social Work Interventions are Recommended

Psychosocial assessment can identify suicidal ESRD patients for counseling and other interventions (Kurella, Kimmel, Young, & Chertow, 2005). Witten (1998) recommends that social workers can assist with dialysis adequacy, anemia, and access, encouraging rehabilitation, exercise, and employment. Nephrology social workers can help enable patients to identify and maximize their resources and develop effective coping mechanisms (Moores, 1983).

CKD Multidisciplinary Team Care (Including an MSW) is Recommended

Multidisciplinary CKD care is associated with fewer hospitalizations and lower mortality (Goldstein, Yassa, Dacourisn, & McFarlane, 2004), and can be used to educate nonrenal community care providers on the unique issues related to CKD patient care (Arthur, Zalemski, Giermek & Lamb, 2000). Social work participation in multidisciplinary patient education has been shown to be important in increasing the number of early dialysis access placements (Lindber, et al., 2005). Successful vascular access leads to better dialysis outcomes, lower morbidity and hospitalizations.

Nephrology Social Work Assessment and Intervention Considerations

It is recommended that comprehensive individual psychosocial assessment of ESRD patients is conducted to maximize patient outcomes (Fox & Swazey, 1979). Dialysis patients have been found to have the greatest adjustment concerns in the first three months of treatment (Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2000, 2001). Renal social work tasks are focused on 'improving the patient's ability to adjust to and cope with chronic illness and the health care system's ability to meet the needs of the patient' (McKinley & Callahan, 1998).

Social Workers Have Been Shown to Be an Important Part of the Transplant Team

Living donor kidney transplants are increasingly popular. Social workers must assess: the donor and recipient in order to gauge any normative pressures on the donor that may influence the decision to donate a kidney, their motivation for donation, their ability to make informed consent, the nature of the relationship between the donor and recipient, psychosocial status, developmental history, possible substance use, and mental health status (Fisher, 2003; Fox & Swazey, 1979; Leo, Smith, & Mori, 2003).

The Following Findings Indicate that Nephrology Social Work Interventions are Valued and Desired by the Patients Whom They Serve:

Family members of dying ESRD patients desired more emotional support and social work intervention and requested that social workers make contact with the family after the death (Woods et al., 1999). Siegal, Witten, and Lundin's 1994 survey of ESRD patients determined that almost 91% of respondents “believed that access to a nephrology social worker was important” (p. 33). Dialysis patients have ranked a “helpful social worker” as being the fourth highest important aspect of care, more important to them than similar nephrologists or nurses (Rubin et al. 1997). In one study, more than 84% of patients relied on nephrology social workers for clinical social work intervention to help them improve coping, adjustment and rehabilitation (Siegal, Witten, & Lundin, 1994). 70% of patients felt that social workers gave the most useful information about treatment modalities, and that social workers were twice as helpful as nephrologists in deciding between hemodialysis and peritoneal dialysis as treatment modalities (Holley, Barrington, Kohn, & Hayes, 1991).

Support for Appropriate Nephrology Social Work Tasks/Evidence of Misutilization of Master's-Level Social Workers

Russo (2002) found that 100% of nephrology social workers surveyed felt that transportation was not an appropriate task, yet 53% of respondents were responsible for making transportation arrangements. Russo (2002) found that 46% of nephrology social workers were responsible for making transient arrangements, yet only 20% were able to do patient education. Tasks such as clerical duties, admissions, billing and insurance matters prohibit effective nephrology clinical social work intervention for patients (Callahan, Witten & Johnstone, 1997; Russo, 2002). Promoting Excellence in End-of-Life Care (2002), a national program office of The Robert Wood Johnson Foundation, recommends that dialysis units discontinue using master's-level social workers for clerical tasks (such as arranging transportation) in order to ensure that nephrology social workers have sufficient time for clinical service provision to their patients and their families. Merighi & Ehlebracht (2004b; 2004c; 2005) in an exhaustive survey of 809 national nephrology social workers found that:

- 94% of social workers did clerical work (faxing, copying), and that 87% of those respondents found these tasks to be outside the scope of their social work training.

- 61% of social workers were solely responsible for arranging patient transportation.
- 57% of social workers were responsible for making transient arrangements, taking 9% of entire social work time.
- Only 34% of the social workers thought that they had enough time to sufficiently address patient psychosocial needs.
- 26% of social workers were responsible for initial insurance verification.
- 43% of social workers tracked Medicare coordination periods.
- 44% of social workers are primarily responsible for completing admission packets.
- Alarmingly, 18% of social workers were involved in collecting fees from patients. This can negatively affect the therapeutic relationship and decrease patient trust.
- The more that nephrology social workers are involved with insurance/billing, the lower their job satisfaction, particularly among social workers who collect fees from patients.
- Nephrology social work job satisfaction is related to amount of time spent counseling and patient education (significantly higher job satisfaction) and insurance-related, clerical tasks (significantly lower job satisfaction).
- Respondents spent 38% of their time on insurance, billing and clerical tasks versus 25% of their time counseling and assessing patients.
- Nephrology social workers who spend more time doing insurance, billing and clerical activities report more emotional exhaustion.
- Nephrology social workers who spend more time doing counseling and patient education report less emotional exhaustion. The authors indicate that these correlations may be indicative of the fact that providing education and direct counseling to patients and family members are activities that are commensurate with the professional training and education of master's-level social workers (unlike billing, insurance and clerical tasks).

Support for Nephrology Social Work/Patient Ratios

CNSW recommends 75 patients per full-time social worker (Council of Nephrology Social Workers, 1998). Texas mandates that nephrology social workers have a patient ratio of 75 to 100 patients per full-time social worker. Nevada has a mandated ratio of one full time social worker per 100 dialysis patients. The Oregon Council of Nephrology Social Workers recommends a ratio of 100 patients to one full-time social worker. Social workers report that high case loads result in a lack of ability to provide adequate clinical services (Merighi & Ehlebracht, 2002). Merighi & Ehlebracht (2004a), in a national survey of dialysis social workers, found that only 13% of full-time social workers had caseloads of 75 or fewer, 40% had caseloads of 76 to 100 patients, 47% had caseloads of more than 100 patients. High nephrology social work caseloads result in lower patient satisfaction and less successful patient rehabilitation outcomes (Callahan, Moncrief, Wittman, & Maceda, 1998). Estrada & Hunt (1998) recommend that increased time is needed for social workers to fully assess patients' psychosocial status. Merighi & Ehlebracht (2005) found that nephrology social workers spend more time providing counseling to patients when they have lower patient caseloads.

In one study of nephrology social workers (Bogatz, Colasanto, & Sweeney, 2005), 68% of all social workers did not have enough time to do casework or counseling; 62% did not have enough time to do patient education; 36% spent excessive time doing clerical, insurance and billing tasks. One participant stated: “the combination of a more complex caseload and greater number of patients to cover make it impossible to adhere to the federal guidelines as written. I believe our patients are being denied access to quality social work services.” (p. 59). Social workers in the study had caseloads as high as 170 patients; 72% of social workers had a median caseload of 125 patients. Social workers have indicated that large caseloads hinder their ability to provide clinical interventions (Bogatz, Colasanto, & Sweeney, 2005). For every dollar invested in patient education, $3–$4 were saved (Bartlett, 1995).

CNSW Support for Master's-Level Social Work Service Provision

The nephrology social worker must be skilled in assessing for psychosocial influences and their interrelatedness in predicting treatment outcomes. The nephrology social worker must also be able to design interventions with the patient, the family, the medical team and community systems at large to maximize the effectiveness of ESRD treatment. The additional training received by a master's-prepared social worker enables them to perform these complex professional tasks and ensure effective outcomes that have a direct relationship to morbidity and mortality. Master's-prepared social workers are trained to utilize validated tools, such as the SF36 and KDOQL, to improve care and to monitor the outcomes of directed interventions, assess the complex variables that these instruments measure (Ellstrom-Calder & Banning, 1992; Lenart, 1998; National Association of Social Workers, 1994), and continually redesign a plan of care to achieve outcome goals. The master's-prepared social worker provides the interdisciplinary team with a biopsychosocial view of the patient's strengths and needs (Berkman, 1996) through use of patient-perceived quality-of-life measures and the person-in-environment model of assessment (Monkman, 1991). Most nephrology social workers provide psychosocial services autonomously as primary providers without social work supervision or consultation. Autonomous practice in an ESRD setting demands highly developed social work intervention skills, obtained in a master's-level curriculum. MSWs are trained to autonomously provide diagnostic, preventive and treatment services for individuals, families and groups in the context of their life situations (Harris, 1995). These interventions assist ESRD patients in developing adaptive behaviors and perceptions necessary to cope with the changes brought about by chronic illness and hospitalization.

Nephrology social workers must be prepared to contribute to the development of clinical pathways to enhance treatment outcomes. Nephrology social workers must have outcome evaluation skills and must understand the interaction among individual systems, the social system, and the medical system as each impacts patients and families. Nephrology social workers must be able to distinguish between normal adjustment reactions and more debilitating and potentially self-destructive emotional reactions, as well as tailor interventions to the individual coping styles of the ESRD patient (Christensen, Smith, Turner et al., 1994). The master's in social work degree (MSW) provides an additional 900 hours of specialized training beyond a baccalaureate degree in social work. An MSW curriculum is the only curriculum which offers additional specialization in the bio-psycho-social-cultural, person-in-environment model of understanding human behavior. Undergraduate (BSW) degrees, or other mental health credentials (MA in counseling, sociology, or psychology, or PhD in psychology, etc.) do not offer this specialized and comprehensive training in bio-psychosocial assessment and interaction between individual and social systems.

The National Association of Social Workers Standards of Classification considers the baccalaureate degree as a basic level of practice (Bonner & Greenspan, 1989; National Association of Social Workers, 1981). Under these same standards, the master's in social work degree is considered a specialized level of professional practice and requires a demonstration of skill or competency in performance (Anderson, 1986). Master's-prepared social workers are trained in conducting empirical evaluations of their own practice interventions (Council on Social Work Education). Empirically, the training of a master's-prepared social worker appears to be the best predictor of overall performance, particularly in the areas of psychological counseling, casework and case management (Booz, Allen, & Hamilton, Inc., 1987; Dhooper, Royse & Wolfe, 1990). Masters-prepared social workers are identified as major mental health service providers in both urban and rural areas (Hiratsuka, 1994).

The additional 900 hours of specialized, clinical training prepares the MSW to work autonomously in the ESRD setting, where supervision and peer support is not readily available. This additional training in the biopsychosocial model of understanding human behavior also enables the master's-prepared social worker to provide cost-effective interventions, such as assessment, education, and individual, family and group therapy, and to independently monitor the outcomes of these interventions to ensure their effectiveness. Renal patients present with highly complex needs on an individual as well as systems level. Social workers are trained to intervene in both areas of need that are essential for optimal patient functioning, and help facilitate congruity between individuals and their environments' resources, demands and opportunities (Coulton, 1979; McKinley & Callahan, 1998; Morrow-Howell, 1992; Wallace, Goldberg, & Slaby, 1984). Social workers have an expertise of combining social context and utilizing community resource information, along with knowledge of personality dynamics.

CONCLUSION

Using this vast information, CNSW members created responses to the COC that will hopefully be incorporated into the next version of the dialysis and transplant COC. We invite you to save this literature review to use in future research and publications as you join us in creating the future history of nephrology social work.

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Promoting Resilience in ESRD: Evaluation of a Group Cognitive-Behavioral Intervention for Patients on Hemodialysis

Jessica Cabness, DSW, LCSW, Assistant Professor of Social Work, Cindy Miller, MSW, LCSW, and Kia Flowers, MSW, University of South Florida College of Arts & Sciences, St. Petersburg, FL

This study examined the efficacy of a six-week group cognitive-behavioral intervention for mediating depression, perceived social support, and quality of life of patients on hemodialysis in west Central Florida. Length of time on dialysis varied from 30 days to over two years. A quasi-experimental multivariate design tested several hypotheses. It was predicted that patients in the experimental group would benefit from the social work intervention as evidenced by improved mood, increased social support, and better life quality than the patients in the control group. The sessions were called "Feeling Better Again: A Life Management Series for People With Chronic Kidney Disease." Patients completing fewer than six sessions were predicted to benefit less than patients completing all six sessions. Length of time on dialysis was also predicted to make a difference in patient responses at pre- and post-test. In this multimethod approach, qualitative data from patient surveys support the quantitative findings, giving the study methodological robustness. The authors propose linking biopsychosocial research with ESRD patients to the resilience construct in order to extend the knowledge base on biological contributors to resilience in adults with chronic kidney disease

INTRODUCTION

Dialysis significantly changes the lives it saves while creating unique challenges for patients with End-Stage Renal Disease (ESRD). Symptom management, limitations on lifestyle, ongoing uncertainty of life on dialysis, and increased dependence are prominent life-altering features in the lives of dialysis patients (Polaschek, 2003), potentially positioning them for depression. The occurrence of clinical depression, as defined in the *Diagnostic and Statistical Manual of the Mental Disorders, Fourth Edition* (DSM-IV-TR) of the American Psychiatric Association (2000), is common among patients on dialysis (Illic, Djordjevic, & Stefanovic, 1996; Kimmel, 2002; Kimmel, Peterson, Weihs, Simmens, et al., 1998; Mazzella, 2004). This study and others demonstrate the prevalence of depression and anxiety in dialysis patients (Beder, Mason, Johnstone, Callahan, & LeSage, 2003; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2001; Estrada & Hunt, 1998; Lopes, Bragg, Young, Goodkin, Mapes, et al. 2002; Soykan, Arapaslan, & Kumbasar, 2003). Because the effects of depression influence patient motivation for dialysis treatment and adherence to renal regimes, nephrology social workers may need to intervene at different points along the dialysis continuum of care. When treated, depression has been shown to be a modifiable risk factor for cardiovascular disease in ESRD patients (Beder et al., 2003); left untreated, suicide ideation and lethal plan may result (Soykan et al., 2003). Accordingly, social workers are choosing interventions for depression to improve survival in ESRD because they recognize the traumatic life changes imposed on patients with chronic kidney disease. Nephrology social workers in dialysis centers are particularly vigilant for the symptoms of depression in this population.

Depressive symptoms may be expressed as non-adherence to renal regimens or the wish to terminate dialysis altogether (Mazzella, 2004). In addition to changes in lifestyle, nutrition, and daily activities, dialysis schedules and severe fatigue related to anemia contribute to problems in maintaining relationships and employment (Estrada & Hunt, 1998). Nephrology social workers are challenged to identify effective interventions to restore ESRD patients to an optimal quality of life in spite of related restrictions. Risk factors for depression among dialysis patients include core beliefs (cognitive schema) related to the disease, perceived stigma associated with dialysis, poor body image, coping style, availability of social support, marital status, living arrangements, employment status, and previous history of mental illness (Callahan, 2001/2002). Since ESRD patients are unlikely to receive treatment for depression from a mental health professional outside of the dialysis center, on-site nephrology social workers have the unique opportunity to assess and monitor patients who may be experiencing depressive symptoms (Johnstone, 2002).

The purpose of the study was to examine the efficacy of a group cognitive-behavioral intervention in mediating depression, perceived social support, and quality of life of patients on hemodialysis in west Central Florida. Johnstone's (2002) qualitative analysis of the "Feeling Better Again" intervention with dialysis patients (n = 5) suggested positive outcomes on a number of measures, including improved mental health, better outlook, and increased quality of life. Like Johnstone's original study, the research reported here was grounded in social work practice in dialysis centers. Similarly, the Florida researchers predicted that the social work intervention would make a difference in how dialysis patients felt about their health status, social support, and outlook on life. The investigators were intrigued to know if changes in these areas might translate into patient cost savings, as evidenced by fewer emergency room visits during the six-week intervention.

METHODOLOGY

A six-week cognitive-behavioral intervention, developed by Johnstone (2002) for ESRD patients, was used with a convenience sample of self-selected study participants. The investigative team used a quasi-experimental, multivariate research design to compare pre-test and post-test scores on depression, social support, and health quality measures. Analysis of variance was used to measure the strength of the associations, and regression analysis was used to determine the effect of length of time on dialysis (LTOD) on depression. Institutional review and approval preceded patient recruitment and the informed consent procedure. A licensed on-site nephrology social worker and MSW intern collected the data to test three hypotheses: (1) The experimental group will show greater improvement in their post-test depression and quality of life (QOL) scores following the six-week cognitive-behavioral group intervention than the control group; (2) patients participating in all six sessions of the cognitive-behavioral group intervention will show greater improvement in their post-test depression and QOL scores than patients attending fewer than six sessions; and (3) social support will emerge as a significant predictor of improved depression and QOL for the experimental group. The independent variables were socio-demographic and background variables (gender, age, race/ethnicity, education, marital status, current living arrangements, availability of social support, employment status, medications, and mental health status). The dependent variables included depression as measured by the seven-item BDI-FastScreen, developed by Beck, Steer, and Brown (2000) for medical patients; self-reported social support as measured by the Multidimensional Scale of Perceived Social Support (MSPSS), developed by Zimet, Dahlem, Zimet and Farley (1988); and patient QOL as measured by the SF-36v2 Health Survey available from QualityMetric, Incorporated. Lower BDI scores indicate low patient distress. The MSPSS scores indicate the adequacy of support from a specific source (e.g., family, friends or significant other) on a 12-item Likert-type scale. Higher scores on the SF-36v2 indicate better health. The data was collected before the first structured class of the six-week intervention and following the last class. The content of each group session is identified below. Smaller groups (< 10) facilitate higher levels of individual participation.

Class 1: Understanding Depression and How to Feel Better Again
Class 2: Cognitive-Behavioral Training: How It Works
Class 3: Balancing Your Thinking
Class 4: Practicing New Skills
Class 5: Reducing Worry
Class 6: Maintaining and Moving Forward

In appreciation for patient participation, gift cards worth 10 dollars from local supermarkets were distributed to patients in the experimental and control groups upon completion of the pre- and post-tests. In addition, during each of the six classes, one participant in the experimental group received by random drawing a gift card, valued at 20 dollars, for dinner for two at a local restaurant.

Sample Characteristics

Twenty-three patients (n = 13 males and 10 females), ranging in age from 30 to 84 years, participated in the study from October to December 2004. About 56% (13) were 49 years and younger. The majority of patients (70%) were African American followed by 17% Caucasian. Native Americans accounted for nine percent, with mixed race accounting for four percent. Nearly 70% reported completing 12 years or less of schooling; 26% reported having completed some college. Concerning marital status, 43% were divorced or separated while 35% had never been married; 13% were widowed; and 9% were married. Forty-eight percent of patients lived alone; nearly 44% lived with a family member; and fewer than 10% lived with a spouse or partner. Sixty-five percent reported having social support; 35% either reported no available support or did not respond to this question. The majority of patients (65%) had been on dialysis from one to two years; 17% had been on dialysis for at least six months but less than one year; and nine percent reported being on dialysis for at least one month but less than six months. Nearly all (87%) were unemployed at the time of the study. Most patients reported taking five or fewer medications, with 39% reporting taking six to 11 or more. When asked about prior treatment to maintain mental health, 78.3% denied any mental health treatment while 21.7% responded affirmatively. The sample characteristics are illustrated at **Table 1**.

Table 1. Sample Characteristics (n=23)

	n	Mean Age
Gender		
Male	13	48.8
Female	10	46.8
Ethnicity		
African American	16	49.1
Caucasian	4	44.8
Native American	2	49.5
Other	1	32
Education	Male (%)	Female (%)
12 yrs or less	85	50
Some College	15	50
Living Arrangements		
Live alone	77	10
With family member(s)	23	70
With spouse/partner	0	10
With other(s)		10
Length of Time on Dialysis		
1-6 months	23	0
7-12 months	15	20
Over 1 year	31	30
Over 2 years	31	50
Daily Medications		
0-5	61	50
6-10	31	50
More than 10	8	0
Prior Mental Health Txmt		
No	85	70
Yes	15	30

Data Analysis

The data were analyzed using SPSS statistical software and SF-36v2 scoring software. A t-test analysis was used to determine between-group differences. *Chi square* analysis was used to determine within-group differences. Analysis of variance (ANOVA) was applied for interaction effects among the variables. Regression analysis was used to determine the effect of length of time on dialysis. The SF-36v2 pre- and post-tests were scored using a logarithmic computer program available for purchase from QualityMetric. A bivariate analysis, using Pearson's correlation coefficient, identified relationships among the variables. The experimental group's responses on confidential Patient Satisfaction Surveys, with comments about the "Feeling Better Again" classes and recommendations, were summarized as qualitative data. Patient responses on the BDI-FastScreen for Medical Patients (The Psychological Corporation, 2000) were analyzed for its test-retest reliability. Cronbach's alpha coefficient (r = .654) suggested only moderate reliability for our sample, appreciably less than the reliability coefficient (r = .84) reported for sample of psychiatric outpatients in the accompanying BDI manual. This finding is thought to be an artifact of the study reported here and not a reflection of the instrument. The Multidimensional Scale of Perceived Social Support (MSPSS) yielded a high Cronbach's alpha coefficient (r = .914), suggesting very satisfactory test-retest reliability over six weeks.

Results

Patients participating in the experimental group reported that "the most helpful thing about the class is getting together and [having] discussion[s] about depression and how to reduce worry"; "redirecting my thoughts was especially helpful." They expressed that being with others with the same disease helped them to realize that "I'm not alone," what Yalom (1985) refers to as universality. The results of the qualitative data, culled from the Patient Satisfaction Surveys, revealed very positive patient responses to the "Feeling Better Again" classes. The patient surveys are summarized in **Table 2**. One of the most salient quantitative findings to emerge from the study was the difference in post-test depression scores of the experimental and control groups. The mean depression score decreased for the experimental group upon post-test administration of the BDI. This finding demonstrates the effectiveness of the six-week group intervention. The control group mean on the post-test depression measure was 2.62; the experimental group post-test mean depression score was 1.33. Thus, we reject the null hypothesis. These data are shown in **Table 3**.

The QOL indicators, measured by the SF-36v2, revealed changes in personal functioning, physical role limitations, body pain, general health perceptions, vitality, social functioning, emotional role limitations, and mental health. A comparison of the experimental and control group pre-test and post-test scores on the SF-36v2 are found in **Table 4**. Overall, the findings suggest that the social work intervention helped to improve the perceptions of physical role limitations, general health, vitality, social functioning, and emotional role limitations of participants in the experimental group. All but two participants in the experimental group (n = 13) completed the six-week group cognitive behavioral sessions. There was no evidence to support the hypothesis that those completing fewer than six sessions showed less improvement in their post-test depression and QOL scores than those patients completing all six sessions. Therefore, we accept the null hypothesis.

Table 2. "Feeling Better Again" Patient Satisfactory Survey Results
<u>Experimental Group (n = 11)</u>

	Do Not Agree	Neither Agree nor Disagree	Somewhat Agree	Yes, I Agree
1. The class was valuable to me as a kidney patient.			9%	91%
2. I would recommend this class to other kidney patients.				100%
3. It helped me to communicate with other patients struggling with depression issues.		9%	18%	73%
4. I am more satisfied with my care at this clinic as a result of the class.		9%	18%	73%
5. I feel more able to manage my depression as a result of the class.		9%	36%	55%
6. I understand more about how depression can interfere with my quality of life as a result of the class.		9%		91%
7. I think my mood is better as a result of this class.			36%	64%

8. What was the most helpful thing about this class for you?
(n =10)
   a. Learn[ed] to control myself when I am mad at others.
   b. Help[ed] me overcome my depression and look at my life as a test.
   c. I better understand my emotional state.
   d. The most helpful thing about this class is getting together and [the] discussion about depression and how to reduce worry. I learned a lot. And another thing—I was able to get out more and do things for myself.
   e. Each class was helpful in general, but redirecting my thoughts was especially helpful. The information was clear and well organized. Also, being with other people with the same illness and listening to their problems made me feel that I was not alone.
   f. The class helped me to understand better about my kidney problem and the problems that comes [sic] with it.
   g. [I learned] that you are not the only one going through the situation.
   h. Knowing [from the class] that you are not the only one struggling. Being able to express and learn from other patients.
   i. Listening to others about their situations.
   j. It learned [sic] me to be a better person.

What could we do to make the class better? (n = 8)
   a. Have more classes.
   b. I think the class was excellent and wouldn't change it.
   c. I think a little more that [sic] [time than] an hour would improve the class because sometimes we had so much to say with little time.
   d. To make the class better, I would have more classes.
   e. Keep having a class on different discussion [topics].
   f. Have it continuously.
   g. I don't know.
   h. Keep have[ing] class[es].

Table 3. Comparison of Experimental and Control Group Mean Depression Scores

	Control		Experimental	
	Depression 1	*Depression 2*	*Depression 1*	*Depression 2*
Mean	1.6667	2.6250	3.5455	1.3333
N	9	8	11	12
Std. Deviation	1.32288	3.06769	2.50454	1.61433

Table 4. SF-36v2 Mean Summary Scores

	Experimental Group		Control Group	
	Pre-test	Post-test	Pre-test	Post-test
PF	32.31	32.31	38.09	36.09
RP	39.71	35.83	37.02	36.0
BP	45.57	50.36	44.16	46.95
GH	35.51	38.58	42.64	46.95
VT	43.25	49.49	48.66	47.58
SF	39.58	42.31	44.85	43.52
RE	40.33	39.03	40.33	45.51
MH	46.16	47.43	46.91	49.69

Note:
PF = Physical functioning
RP = Role limitations (physical)
BP = Body pain
GH = General health perceptions
VT = Vitality
SF = Social functioning
RE = Role limitations (emotional)
MH = Mental health

As hypothesized, social support emerged as a salient factor in improved mental health for patients in the experimental group. The null hypothesis is therefore rejected. There was also a statistically significant interaction effect between living arrangement, marital status, and mental health, which accounted for 23% of the variance explained in pre-test depression and MSPSS scores. Similarly, an interaction effect emerged between living arrangement, marital status, and medications, accounting for 16 percent of the variance explained in the post-test scores on the BDI-FastScreen and MSPSS. This finding suggests that collapsing the sociodemographic variables (e.g., living arrangement and marital status) might reduce the ambiguity of an interaction. There was no finding of within-group differences. When pre-test depression was submitted to regression analysis by length of time on dialysis, LTOD approached statistical significance (.91).

Bivariate analysis, using Pearson's r, revealed a moderately strong, significant, negative association between depression at post-test (Time 2) and perceived social support at Time 2 ($r = -.581, p \leq .01$), suggesting that as depression decreases patients experience more adequate support of family, friends, and significant others. A similar association was found between number of medications that patients reported taking and perceived social support at Time 2 ($r = -.446, p \leq .05$). The finding of a significant inverse relationship suggests that patients taking fewer medications feel more adequately supported by family, friends, and significant others.

DISCUSSION

A convenience sample of dialysis patients were invited to attend a series of six classes called "Feeling Better Again: A Life Management Series for People With Chronic Kidney Disease." Flyers were posted in common areas of the dialysis center and distributed to each patient as well. The nephrology social workers explained the aim of the research and were the point of contact for additional information. The posters encouraged the patients to sign up and become eligible for a gift certificate drawing. As the patients seldom received gifts while being dialyzed, the research selection process generated some patient excitement and enthusiasm. In a quasi-experimental research design, 23 patients self-selected and were randomly assigned to the experimental or control group. Those in the experimental group received the six-week group intervention and opportunities to win a weekly raffle drawing for dinner for two; the control group participated in the normal schedule of dialysis center activities with no other patient incentives available to the group until post-test completion.

The center nutritionist was aware of the study and encouraged the social workers to purchase gift cards to restaurants where the patients might make healthy, nutritious food selections. The nutritionist then discussed health food choices during chair-side visits with each patient, irrespective of the patient's status as a study participant, to ensure equal treatment. Patient inducements, such as gift cards, may have influenced patient decisions to participate in the study. It may be argued that the results were biased by the patient incentives, thereby creating a methodological constraint. To examine this issue further, the authors exhort research that replicates the study, both with and without patient inducements.

In this study, the majority of females were women of color. They were more highly educated and tended to live with family members. These women were younger than their male counterparts, but had been on dialysis for longer than two years, at a rate higher than the male study participants. This finding has implications for community-based prevention strategies in west Central Florida to target women at risk for kidney disease toward the goal of reducing gender and racial disparities in ESRD.

CONCLUSION

Attending six weekly structured, group cognitive-behavioral classes had the intended effect of improving depressed mood, increasing social support and social functioning, and helping dialysis patients to feel better again. The findings of the research suggest consistency between the qualitative and quantitative data, adding to the robustness of the research design and providing a multimethod approach for replication by nephrology social workers. The experimental group felt that the class was valuable to them as ESRD patients, and all experimental participants indicated that they would recommend the class to other dialysis patients. The majority recommended more classes to deal with a range of issues pertinent to kidney disease. The self-reported findings suggest that the experimental group benefited at both the individual and group levels. Individual patients realized that they "were not alone" dealing with issues of chronic kidney disease and, collectively, they benefited from some therapeutic aspects of group process (e.g., instillation of hope, universality, imparting information, interpersonal learning, altruism, and development of socializing techniques (Yalom, 1985)). None of the participants in the experimental group were hospitalized during the first six weeks following the study. This finding has the potential for cost savings associated with emergency department visits and hospital re-admissions. More research is needed to determine if there is an association between the intervention and lower hospital utilization.

One of the study's limitations is the small sample size. This precludes generalizing the findings beyond the west Central Florida sample. Statistically significant associations were also limited to bivariate analysis of the independent and dependent variables. A larger sample might ensure greater significance, allowing the investigators to make a definitive statement regarding within-group and between-group differences as well as re-test the efficacy of the intervention. Nephrology social workers are encouraged to replicate the study as confirmation of evidence-based practice.

The findings of improved mood, positive changes in perceived social support, and improved quality of life are consistent with the extant literature on resilience. Resilience refers to the human capacity to overcome traumatic or aversive events (Curtis & Cicchetti, 2003; Egeland, Carlson, & Sroufe, 1993; Fine, 1991; Luthar Cicchetti, & Becker, 2000; Masten, Best, & Garmezy, 1990). Over the past 30 years, the empirical literature examining the resilience construct has shown strong associations between internal factors, such as cognitive schema resulting in depressive disorder and low self-esteem (e.g., Cicchetti, Rogosch, Lynch, & Holt, 1993; Luthar, Cicchetti, & Becker, 2000; Rutter, 1987; Werner, 1993), and external factors, such as biological conditions, social support of family, friends, teachers, significant others and social networks (e.g., Curtis & Cicchetti, 2003; McMillen, 1999; Palmer, 1999). Although the preponderance of resilience research has examined outcomes with neglected and maltreated children and adolescents (e.g., Masten, Hubbard, Gest, Tellegn, Garmezy, & Ramirez, 1999; McGloin & Widom, 2001), there is beginning evidence to support the inclusion of resilience, as process and outcome, in research with ESRD patients. White, Richter, Koeckeritz, Lee, & Munch (2002) point to the need to examine cross-cultural differences in family resiliency of hemodialysis patients. Dobrof and her colleagues (2001) write that "the majority of patients do have the familial and social supports that in other studies have been shown to buffer against depression, increase compliance, and contribute to positive health outcomes." In the present study, the nephrology social workers promoted resilience in ESRD patients through the use of a highly effective weekly group cognitive-behavioral intervention. Replication of the study is encouraged to compare the research findings, refine the instruments as needed, and examine the utility of the resilience construct in ESRD.

Note: *This study was funded by the NKF-CNSW.*

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"So You Want to Be a Pediatric Renal Social Worker…"

Sandra K. Coorough, ACSW, LCSW, BCD, C-ASWCM
Pediatric Renal & Transplant Social Worker, Phoenix Children's Hospital, Phoenix, AZ

A NEW LIFE; A NEW CHALLENGE

When a baby is born, parents look for 10 fingers and 10 toes. Few ask specifically if the baby's kidneys are working. When problems are diagnosed within the first few days, Mom and Dad spend what they had anticipated as initial happy moments in a neonatal intensive care unit (NICU) instead. The moments are filled with fear and guilt and with questions that are not always easily answered for them.

All the dreams and hopes that developed over nine months are frozen in place. All the expectations are on hold, and fear and worry take over. The loss of those happy times can wear on a couple. If there were issues prior to the birth, these issues will surface and demand attention. If there are older siblings, Mom and Dad struggle to provide care for them, answer their questions, and shield them from the fear.

CASE STUDY: KEVIN, AGE FOUR MONTHS

Kevin was diagnosed in utero. His mother was referred to the pediatric nephrologist during her pregnancy. She was aware of the difficulties and felt initially that she was prepared for Kevin's NICU stay and need for dialysis.

She and the father had a tenuous relationship, which unraveled during the pregnancy. He did not attend the birth and tentatively visited his son in the NICU following a confrontation with mother. Alternate visiting times were set up, which reduced some of the nastier encounters.

During the eight weeks in the NICU, Mother breast fed, rocked Kevin, and took in as much information about her son's medical status and needs as she could. Mother trained to do the peritoneal dialysis and did quite well. With the social worker's recommendation and assistance, she prepared her three older children for Kevin's homecoming. The social worker addressed concrete issues and plans for how this single mother of four was going to maintain her career as a CPA.

During the last two weeks of hospitalization, Dad decided that this was his only son and he needed to be a part of his life. Not a good plan as far as Mother was concerned. She had begun to understand just how much time and work it was going to take to care for Kevin. She tried to talk to Dad about this, but he interpreted the discussion as Mother's way of trying to get him out of the picture. So, she turned to the treatment team.

A conference was set up with Dad. During this conference the nephrologist, PD nurse and social worker attempted to explain Kevin's medical needs. Dad's focus was on visitation and his father's rights. The team supported his desire to see his child while explaining that training one parent to manage the PD was a means of reducing the opportunities for infection. Dad said it was required that he be able to take his newborn, PD-dependent infant to his own apartment at least three to four times per week for up to eight hours. All attempts to educate him regarding the difficulties in this plan went unheard. At a court hearing that same week, Dad was able to gain four days of visitation at the Mother's house. Within two weeks of Kevin and his mother being discharged home, Dad and Mother had difficulties with this plan, which resulted in the father calling the police on two occasions. Both attorneys contacted the social worker, as had been recommended by the nephrologist prior to Kevin and his mother's discharge from the hospital. The attorneys had difficulty understanding Kevin's needs and their ability to advocate for their clients was stymied. The social worker also recommended that a guardian ad litem be appointed for Kevin, given the issues between Mother and Dad. Both attorneys thought this was a good idea. Dad was unsure of the idea, but Mother supported it wholeheartedly.

When Mother brought Kevin in for a routine biweekly weight check, she was clearly not coping well. The PD nurse and dietitian contacted the social worker immediately. During the visit, Mother reported that she had lost 15 pounds, was struggling with trying to adjust her schedule, and was concerned about Dad's visits. Dad did not understand that placing his son on his tummy was not a good idea. He argued with Mother, insisting that this was the way he had been told to do it by his mother. Mother had asked him to work with the PD nurse so he could better understand Kevin's medical needs, but he never got around to doing it. The social worker suggested that Mother and Dad come in with their attorneys to see the treatment team during a routine PD visit. This was an attempt to get everyone on the same page with a consistent plan in place.

Everyone arrived on time for the PD visit, and the nephrologist proceeded to go through the routine questions and to make the necessary changes to keep Kevin on track medically. Kevin had grown a little and had put on a tiny amount of weight, all good signs of Mother's hard work in caring for her newborn. Dad understood very little of what was going on, as he did not know much about Kevin's medical status and kidney disease. When Mother requested that the number of visitations be reduced, as they caused her serious stress, Dad's attorney refused to negotiate. The team tried to explain the seriousness of Kevin's status and the need for consistency and reducing opportunities for infection. Mother requested that Dad come to all medical visits. She suggested using these appointments as one of the visitations. He agreed to do this. The social worker made arrangements to see Mother, Dad and Kevin on a weekly basis until the attorneys could work out a better plan. The dietitian offered to do weekly weight checks and the PD nurse indicated she would see Kevin as well. But the work has just begun in caring for Kevin. The treatment team knows that there will be more challenges in the future.

Pediatric treatment teams see these patients and their parents on a routine basis. Creative management demands that each member of the team understand the broader picture. In this case, Mother and Dad have a long way to go before they can work together for Kevin. Both are dealing with issues of loss, anger, and disappointment: for themselves, their own relationship and their son. It is important for the social worker to provide the opportunities for these parents to address their issues and concerns. If they are not resolved, the treatment team will see the signs: poor medication maintenance will show in lab work; missed appointments will increase; and attention to details will no longer be evident in overall care.

TODDLER'S TRIALS

If the social worker intervenes early in the diagnostic and treatment process, parents can use the systematic approach to problem solving as a format by which they address the inevitable issues that arise in caring for a pediatric CKD patient.

If the diagnosis of CKD comes during babyhood, questions about what was done wrong or what was missed are often the initial response. Parents want to know why the pediatrician did not know about the problem sooner and why they did not recognize symptoms. Between keeping the baby comfortable, watching the baby endure the testing and blood draws, and trying to hear everything the doctor, the nurse, and the dietitian are trying to explain, parents often shut down despite themselves. That's when the social worker is essential to the care of the baby and the family. The initial intervention that is done by the pediatric nephrology social worker makes it possible for the family to make decisions that will only be the beginning of a lifelong journey.

CASE STUDY: KAT, AGE 2.5 YEARS

Kat is an undisciplined child who appears to have enough energy to run the world in her spare time. She was referred after it was discovered during a visit to the pediatrician's office that there was protein in her urine. It was a routine referral to the specialist. Mother did not initially take it seriously when it was first found, over nine months prior to our seeing this child.

Upon entering the exam room the social worker encountered a child who was climbing all over the furniture, exam table and making a serious effort to conquer the higher counters. Her mother, who was five months pregnant and had little energy for dealing with her daughter's behavior, was sitting watching the child conquer the room. She readily admitted this and asked that the social worker try to help her figure out what to do. Pediatric renal social workers see and hear this on a daily basis: a 19-year-old mother, unprepared for motherhood. She admitted that she wanted children but it had all happened too fast. Kat's father became scarce upon learning that the mother was pregnant with Kat. She did not have the money for prenatal care, so she did not see anyone until she went into labor at the county facility. Now her child must be monitored, as she has been diagnosed with nephrotic syndrome and hypertension.

The frequent clinic visits, which also require either a urine sample or a blood draw, are very difficult on Kat and her mother. Mother has difficulty seeing and hearing Kat object to the blood draws to the point that she has asked that one of the staff hold Kat for this procedure. She cannot get a urine sample at home so this is also part of the process. Mother tries to understand what the nephrologist is explaining regarding Kat's disease and difficulties but has told us all that it is more than she can take in. The social worker has developed a relationship and participates in the clinic visits. Despite the nephrologist's efforts to explain the medical issues as clearly and simply as possible, the social worker has noted that mother appears to listen but does not really hear what he is telling her. That blank look says it all.

The social worker has been able to take small pieces of information that Mother needs for Kat and interprets them for her. This has increased Mother's understanding that she needs to keep the clinic visits and to fill the prescriptions. She doesn't really understand what the medications do, but she knows that without it, this child blows up like a balloon. She also understands that Kat's behaviors have been influenced by the medications. Unfortunately, she uses this as an excuse to avoid disciplining Kat. The social worker is still working on that one.

Mother has begun to verbalize that caring for Kat's nephrotic syndrome will take vigilance on her part. With the help of the social worker, she has been able to arrange for respite care so she can go to parenting classes. She has begun to see a family support specialist through the state-funded mental health program and she has kept all of the appointments made for Kat. Mother talks freely with the social worker about how the new baby will take even more time and how frightened she is of all the responsibilities. She worries that the new baby will have the same problems. With education, counseling, and appropriate systems support, this mother has an opportunity to provide good parenting and to participate effectively in her daughter's medical care.

CKD KIDS GO TO SCHOOL

If the diagnosis is made in a school-age child, additional components are added to the picture.

To this point, there has been the child, the parents, siblings, extended family, the family pediatrician, and the CKD treatment team. Now teachers and peers, cafeteria choices and physical education issues, and missed school days are added to the stress index. Parents begin to worry about how well the child is learning. The social worker addresses growth and development concerns on a routine basis. It is important to keep a CKD youngster in school. In order to do so, the social worker must address the child's emotional responses to the diagnosis, the manner in which the child is being parented, the teachers' response to dealing with a child who does not necessarily look sick (like someone with leukemia), and the doctors' appointments that take away from instruction time. Add to this the challenge of a child on dialysis who must learn how to navigate the American school systems' cafeteria choices. So the school system, with all of its requirements, expectations and restrictions, enters the picture.

CASE STUDY: ALEX, AGE 10 YEARS

Alex is on peritoneal dialysis. He was hospitalized in the summer, during which he had his catheter placed and his mother was trained to put him on PD every night. They did well for the remainder of the summer, but now that school has begun Alex is having his difficulties. He has an older brother and two younger sisters. His older brother began middle school that year and was not available at their elementary school. His two younger sisters were just beginning school. Alex was returning to a familiar school and some of his friends from the previous year. He had a new teacher and a new school nurse.

Every morning Mother must get Alex off his PD, all of the children ready for school, feed them, and get herself dressed and ready for work. She was struggling with the schedule but Alex had only been tardy twice. Mother had asked the social worker to work with the school so they would all understand that Alex had some special needs. The social worker called the school nurse, looked into an IEP (Individual Education Plan), and had the doctor complete the chronic illness forms that would allow the routine absences for the monthly PD clinic visits.

About five weeks into the first quarter, Alex's teacher called the social worker, asking how long he would be hospitalized. Since Alex was not in the hospital, this came as more than a surprise. The social worker called the home to find that mother was unaware of Alex missing any school. An investigation ensued.

Alex and his sisters took the school bus every morning. Upon reaching school, Alex went in one direction and his sisters in another. He spent the day in the neighborhood, but had been able to avoid detection. He never did share how he did this. When he saw the school buses line up to take the children home, he made his way onto the campus and simply got on the bus to go home.

When the social worker spent time talking to Alex, he shared that his best friend had asked him about the tube in his belly and then did not want to play with him anymore. He also had trouble in the cafeteria because he couldn't eat the food: cheese enchiladas, macaroni and cheese, and hot dogs. And he hated going to the school nurse to get his medications. The physical education teacher wouldn't let him play dodge ball, so he had decided that going to school just wasn't worth the effort. The social worker assured Alex that these were problems that she could help him work out if he were willing to do so. She worked with his mother to better understand the changes and concerns that Alex was experiencing, despite the fact that he was not telling her about them.

A visit to the school was made, which offered the school nurse, teachers and physical education coach an opportunity to voice their fears and concerns. Alex thought it was a good idea for the social worker to help him talk with his classmates about his PD. This proved very helpful, as many of them had questions which, when answered, allowed them an opportunity to tell Alex that they cared about him and wondered what they could and could not do when playing with him.

Alex returned to school and has done well since.

The social worker who is available to problem-solve with the child, the family and the school system has a direct impact on that child's educational future. Children can be very accepting of new things but are frightened of things that adults do not want to talk about with them. Once the conversation with his classmates started, Alex and the social worker were able to deal with some amazingly sophisticated questions. Too often we adults underestimate children.

TEENAGERS…WHAT CAN BE SAID?

When the child is diagnosed with CKD in adolescence, adherence to treatment regimens and medication compliance can become a battleground. Unless they clearly understand the disease process and the consequences if recommendations are not followed, parents can be as much a detriment to care as the adolescents themselves. The social worker often deals with these kids and their parents. Lab work that is indicative of issues with parental monitoring and adolescent nonadherence are issues dealt with by the treatment team routinely. In the pediatric setting the social worker is seen as <u>the</u> active team member. The social worker assesses the patient and family, validates and supports the strengths, instructs and counsels on how to address the areas of concern, and monitors progress. Sometimes the social worker mediates between the teen and the treatment team.

CASE STUDY: BEV, AGE 16 YEARS

Bev's diagnosis came as a complete surprise to her and her parents. She had gone to her pediatrician for a routine history and physical in order to play basketball for her high school squad. Within a few short weeks of that visit, nothing in Bev's life was routine. She chose to go on hemodialysis, as she did not like the idea of a tube coming out of her tummy.

Her parents tried to maintain their routine and to manage the stresses of this situation, despite all the difficulties. They did not want this problem to make any major changes in their lives, believing that this was the way to normalize the diagnosis. They wanted Bev to take responsibility for her medications and to watch her diet. They insisted she keep all of her honors classes and asked that we have the hospital teachers work with her while she was on hemodialysis so she could keep up.

Bev tried her best for the first quarter of school. She arrived on time for her dialysis, worked on her school assignments, took all of her medications as prescribed and ate only what was best for her. However, by the end of that quarter she was withdrawn and moody. She rarely smiled and did not want to interact with the hemodialysis nurses. She did not want to get to know any of the other kids on hemodialysis and avoided all activities in the unit.

The social worker noticed the changes and made time to talk with Bev. Expecting to meet resistance, she was surprised at how quickly Bev was willing to share her fears, concerns and anger. She admitted that she "played" with her meds and didn't try very hard when it came to her honors math and science classes. She shared that her father tried so hard to avoid dealing with the diagnosis and treatment that she felt like a "weirdo."

The treatment team became frustrated with Bev and her parents. They saw Dad as uncaring and rigid. They saw Mom as distant and cold. The social worker met with the parents and was able to help them deal with the loss, guilt and anger they were working so hard to avoid. Bev and her parents were able to joke about the "dialysis machine under the living room carpet" and to start to talk about the future.

After consistent education and counseling, the social worker was able to help this teen and her parents realign their priorities, understand how to incorporate the medical regimen into their daily lives and focus on planning for transplant. The social worker worked with the treatment team to see the parents in a different light.

ADULT OR "BIG" KID

Most of the young adults that the nephrology social workers care for have been diagnosed sometime prior to this stage of their lives. Consequently, the issues that surface are ones that have had the time and practice to be problematic. Young adults crave independence. On the other hand, some are so dependent that they do not want to be responsible for anything and leave all responsibility to their parents. Parents accustomed to years of worry and vigilance find letting go difficult. And some parents are so weary from the long battle that they surrender under the stress.

Pediatric social workers attempt to mediate, instruct, and counsel in these cases.

CASE STUDY: HANNAH, AGE 19 YEARS

Hannah has had two kidney transplants. Her mother donated the first kidney when Hannah was 15. Despite parental vigilance, she lost that kidney when she was 17. When it was suggested that they go home and try to locate the immunisuppressant medications following her emergency admission to the hospital for rejection, they returned to confront Hannah with the hundreds of pills that she had hidden between her mattress and box springs.

Following two years on dialysis, Hannah was ready for another transplant. The transplant team agreed that the therapy work she had been doing had made significant changes in her level of responsibility and understanding about what was needed for future transplant success. Hannah and the social worker had identified issues, set goals, and worked on preparing Hannah for a successful second transplant.

Her father made the donation this time. As she recovered, Hannah started to make plans to complete her education. She wanted to become a teacher. She had been researching colleges on the Internet and had decided on a small college in a smaller city about 100 miles north of her home. Mother and Father were not happy. They both feared that, without their constant supervision, Hannah would lose this kidney. They worried constantly that Hannah would not follow through with medications, would "go wild" over boys and would not be able to do the class work.

With counseling, both Hannah and her parents were able to agree that she could manage this life transition with their support. They were willing to try to step back a little and allow Hannah the opportunity to experience the normal failures of a young adult.

COMMENTS

There are few places where social workers have the level of access to so many people under such ripe circumstances as in a kidney treatment situation. Pediatric renal social workers listen, assess, counsel, advocate and educate. They are the first line of defense that addresses the cyclic issues presented in emergency rooms, outpatient clinics, hospitals, and doctor's offices. They have an opportunity to positively impact the way a family grows and develops.

The pediatric renal patient will live longer and will become the adult patient of the future. What we as pediatric renal social workers do now will impact that future. And what we do will also have an impact on the adult social worker who will care for our patients when they are adults. That is why it is so important for both the pediatric and the adult renal social worker to understand the intricacies of patients who start their journeys at birth or during childhood. What patients learn as children is what they will do when they are adults.

NOTE: A condensed version of this article appeared in the Spring 2006 issue of *Renalink.* JNSW

An Antidote to the Emerging Two-Tier Organ Donation Policy in Canada: The Public Cadaveric Organ Donation Program

Stephen Giles, MSW, Social Worker, Movement Disorders, Centre Toronto Western Hospital, University Health Network, Toronto, ON Canada

In Canada, as in many other countries, there exists an organ procurement/donation crisis. This paper reviews some of the most common kidney procurement and allocation programmes, analyses them in terms of public and private administration, and argues that privately administered living donor models are an inequitable stopgap measure, the good intentions of which are misplaced and opportunistic. Focusing on how to improve the publicly administered equitable cadaveric donation programme, and at the same time offering one possible explanation for its current failure, it is suggested that the simple moral principle of "give and you shall receive," already considered by some, be extended further. This would allow for those who are willing to sign up to be a public cadaveric donor be given a priority for receiving an organ donation should they ever require it. It is argued that this priority may provide the motivation to give that is so far lacking in Canada. This model is called the Public Cadaveric Organ Donation Program.

Much has been written about kidney procurement and allocation programmes and the increasing gap between the availability of kidneys for transplant and the need for them.[1–4] In addition to the good news that there has been a "gradual increase in the donor rate,'' data also show that "donor programs are maximizing the number of organs retrieved and transplanted from cadaveric donors."[5]

However, despite that good news, in Canada the rate of transplants has not kept pace with the growing transplant waiting list, with kidney transplants representing nearly 80% of all patients on the Canadian transplant waiting list.[5] Consequently a national coordinated and comprehensive strategy was proposed by Health Canada to overcome the poor donation rate.[6] However as of spring 2003 this strategy still has not been implemented. In 2000, Ontario acknowledged the crisis and, acting alone, introduced new legislation establishing a new governmental agency, with the goal of doubling organ transplants in five years. The Ontario government hopes to do this by "maximizing donor opportunities, in order to increase the number of donors for organ and tissue donation."[7]

In British Columbia, the average wait for an adult cadaveric kidney transplant in 2001 was 50.1 months, up from an average wait of 28 months in 1997.[8] Cecka notes, "until cadaveric kidney donation rates increase, living unrelated kidney donation represents an important alternative to dialysis."[9] As a result of the growing crisis in the shortage of organs for donation, new donor models have been developed in an attempt to expand the donor pool. In Ontario the percentage transplants from living donors has steadily and dramatically risen from 19% in 1990 to 76% in 1999.[10] Additionally, Toronto General Hospital in Ontario is "currently expanding the living donor transplant program."[11] However, the expansion of the donor pool is the result of many factors that include medical advances along with pragmatism, both of which are underpinned by a sense of extreme urgency. When combined, these factors are forcing an ad hoc policy that is lacking foresight. Thus it is time for an evaluation of where we are at this point in organ donation policy, and ask the question: Is this where we want to go?

PUBLIC AND PRIVATE DONOR MODELS

Many models have been developed to collect and allocate available kidneys for transplant. I shall argue that they can be divided into *private* and *public* models. Traditionally the distinction between *private* and *public* programmes is based on the premise of which party pays for the service. If the government pays for the service then it is a public programme, whereas if the individual pays for the service it is considered private. With regards to kidney transplants, the cadaveric waiting list is a public service as the government fully insures its costs. In the cadaveric donation and living donation programmes the cost of the transplant medical services will be covered for both the donor and the recipient. The living donor programme is a somewhat

Abbreviations: CD programme, Cadaveric Donation programme; LRD, living related donor; LUD, living unrelated donor; NDD, non-directed donation; PCODP, Public Cadaveric Organ Donation Program; PE, paired exchange.

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more complex than the cadaveric programme however. For example, on occasion the recipient has a living donor who lives in another country; the cost of that person's travel to Canada and all related expenses will not be covered. In addition to air travel, these expenses may include loss of earnings, meals, and accommodation—not to mention possible associated health risks. Beyond these large financial costs, there is also a requirement for social capital: there has to be someone who is willing to be a donor. As a result, Canada has both a public cadaveric donor programme that is fully insured requiring no private funds and a living donor programme which may or may not require private financial resources and will definitely require private social resources.

In Canada there is currently only one kind of fully public programme: the Cadaveric Donation (CD) programme. In this model the kidney from someone who has passed away, and is not related or known to the recipient, is transplanted into a living recipient. In Canada, this is a provincially run programme, where donors must opt in or give consent to be a cadaveric donor. If they are willing to donate their organs upon death, typically this information is placed on their driver's license or healthcare card. If they do not opt in, or do not give consent, it is then understood that they do not wish to donate their organs. However, final consent goes to the family if they are involved.[10]

When one has no social capital one cannot receive a living donor transplant. If you have the social capital but do not have financial resources, you may also not receive a living donor transplant. In this way living private models are not available to the general public unless they have the social and financial resources. Consequently, it is societies most vulnerable, those who are socially isolated and have limited financial means, who will most likely not receive a living donation.

In the living related donor (LRD) model, the kidney of the living biological relative of the recipient is transplanted from the donor, with the negotiation being made between them. In the living unrelated donor (LUD) model, the possible private donor pool is extended beyond the LRD, to include people such as spouses, close friends, and people who are "emotionally related'' to the recipient. Like the LRD model, once again the agreement is negotiated privately between the donor and the recipient. Paired exchange (PE) is also private in nature and is essentially an extension of the LUD model, although its private nature may be extended to include the hospital or possibly others who help find a medical match. Here a person who requires a kidney, and has someone who is willing to donate (whether they are an LRD or LUD) but is not a medical match, is paired with another person who also has a donor who is not a match. The two donor recipient pairs then undergo a simultaneous transplant.[12]

Another interesting model is the non-directed donation (NDD).[13] This model appears to straddle the private and public divide by having the regional transplant centre offer itself as an intermediary between the donor and recipient. In NDD someone has contacted the transplant unit and offers to donate a kidney to anyone who needs it. In this way, it appears public because the donor and recipient do not initially know each other, although the hospital can make provisions for them to meet later, if they both request it. However, NDD is not public in the sense that the donor has chosen to donate to a certain hospital. Further, the transplant centre does not make the resource available to the general public, but instead maintain the resources as private, for its own patients.

PUBLIC VERSUS PRIVATE

Limitations of the donation models

In Canada, the CD programme's current pool of donors is not large enough to meet growing demands: not enough people are signing up for it. Consequently, as a public programme, it is failing the public. LRD, LUD, and PE are alternative models developed to address the waiting list problem of the CD programme. With these models the problem of donor shortage is not addressed on a societal or public level, but is instead being shifted to the individual. That is, if a person has availability of resources on a personal or private level—whether they have financial or social resources—they will be transplanted sooner. If not they are placed onto the CD programme list, with a waiting time substantially longer than NDD, LRD, LUD, and PE.

As a result, these private models appear to have created an inequitable two tier system—one for those who have social and financial capital, and one for those who do not. Moreover, those who have access to the private programmes also have access to the public programmes: if they cannot locate private resources they can always return to public resources. Now, it may be said that those who leave the public list to pursue private donation programmes will increase the resources for those who are on the public programme. This may or may not be true, but if they return the list then grows. This may cause a fluctuation in waiting times, and deprive those on the list from a predictable wait, thereby increasing the anxiety already experienced by being on the waiting list. However, it is the ability to move between the private and public models which is not equal: the choice to move between the two is a privilege of those who have the resources.

The NDD model is interesting because prima facie it seems to have established a way for a small "public" style, or local programme to be based on an equitable model of distribution. They have tried to establish equity by ruling out donations that are targeted to a particular race or sex, which would appear closer to a private negotiation. It does however differ from the other public programme (CD) in that the donor is living, and that it is not a large-scale public programme. Therein lies the problem. Without being a public programme it has retained elements of selectivity and privacy—that is, the donor may specifically select whom or which kind of person receives the donation, by privately selecting which hospital or region to donate to. This is problematic because hospitals may—and quite often do—serve specific socioeconomic, ethnic, and religions populations. Thus donors are still able to choose, to some extent, a target population that is represented by a certain hospital or region. In this way the NDD programme is vulnerable to charges of selection on a macro level. While attempting to rebuff attempts of donor direction, by employing the criteria of nondirected donation, they still must accept that their hospital has been *selected* by the donor, thereby placing their model closer to the realm of a private rather than public programme.

Consequently all of these models (LRD, LUD, PE, and NDD) have elements of private donor selection. The exception lies with the CD programme, which is the best attempt at a nondirected, public (and therefore equitable) donor programme. Moreover, as public administration is a principle of the Canada Health (1984), models other than the CD programme appear to have run roughshod over the spirit if not the legalities of the act.

Reinvigorating the CD programme

There is no doubt that there is room for improvement within the CD programme for it to become more efficient with resources. Yet the resolution of the problem will take more than this for, as Hoffenberg states, '"the solution lies in increasing the supply."[14] I would like to argue that the central problem lies outside of the realm of efficiencies and comes down to the plain fact that not enough people are signing up to donate their kidneys after death. Why is this so?

One simple reason I suggest is that people do not see the benefit for themselves in consenting to be a cadaveric donor. That is they receive nothing, or at least not enough, out of such an act. In recognition of this problem, the USA based Organ Procurement and Transplantation Network and the United Network for Organ Sharing has recently endorsed US legislation, which would study incentives for donation.[15] Among the recommendations are a '"medal of honour" and reimbursement for the donors' funerals. Adding weight to the idea of incentives, which still remain solidly symbolic and not financially centred, Delmonico *et al* have also recognized the limits of altruism and volunteerism.[16] In doing so they have endorsed incentive based ideas such as (1) the medal of honour, (2) reimbursement for donor's funeral expenses, (3) paired exchanges, (4) medical leave for donation, (5) donor insurance, and (6) ensuring access to organs for previous donors.

The proposal of these incentives is helpful as long are they are considered as ways to protect and improve the existing public programme—CD.

A benefit of giving is receiving

Perhaps the most interesting incentive offered by Delmonico *et al* is (6) *ensuring access to organs for previous donors*. Within the traditional system of allocating points for prioritising donors, they suggest, "the need for a transplant in a previous kidney donor should constitute the highest priority in the allocation of organs.''

They are suggesting an important moral concept: prioritizing transplants to those who have already donated. They seem to be saying that if you are willing to give, then you shall receive, and because of your ability to give, your future potential need shall be given the highest priority. I would like to extend this idea to the general CD programme, but before doing so it is interesting to note that elements of the PE model have also incorporated the idea of *if you give you shall receive*. That is by giving your kidney to someone else other than your initial intended recipient: if your kidney is not a medical match to your intended initial recipient, your initial intended recipient shall receive a donation from someone else who is a medical match for them. Simplified, it can be stated as this: if you give, your loved one will receive, and by extension so shall you.

Why not say that those who are willing to give and sign up for kidney donation upon their death will receive the benefit of having a priority to receive a kidney transplant if they require one during their lifetime? Acknowledging the limits of altruism and volunteerism, this idea recognizes the self motivated desire for giving. Indeed it also offers one explanation for the failure of the CD programme and the rise of other programmes where the benefit is more immediately tangible, as in such cases where people who donate see the recovery of their own loved ones. But the only thing which may be more important than seeing one's loved ones recover, I am suggesting, is knowing that one's gift may actually benefit oneself—by prolonging one's own life. In this way giving, and the receiving of benefits which come from it, can be seen as a self-interested interaction that promotes both one's own wellbeing and that of others.

It seems plausible that many people would immediately see the benefit of signing an organ donation card, knowing that they would receive the benefit of a transplant priority for doing so. Of course, that this personal health benefit would also help others in need would be a factor that in itself may be reason enough for some to donate; for those for whom it would not be enough, the benefit would be a compelling reason to donate to the CD programme. What of those who did not sign up? Would we have to say that their gamble failed? I do not believe so. Those people who failed to sign up and subsequently found themselves in need of a transplant would still be placed on the waiting list but would be ranked below those who had signed up. However this would not preclude them from accessing the private models available. More importantly, if people were willing to donate but unable to do so for medical reasons or other reasons beyond their control it would not be held against them.

The main principle here is that if you are willing to donate, you will receive priority for transplantation if you should require it. This model is based on the argument that while people are healthy, donation is not appealing—which may offer another reason for the lack of increase in general rates of organ donation. If this model was publicised, people who were not willing to donate to traditional CD programmes may reconsider when they realize that they will not receive preferential treatment.

As a result, it is hypothesized that by increasing the motivation for donation, by connecting the impersonal and distant policy to the personal lives of the public, eventually this policy would increase the pool of donors. One of the impacts of such a policy would be for the general public to realize that they will receive benefit from donation to such an extent that incentives would no longer be required.

Kleinman and Lowy presented support for a model similar to this.[17] Noting the problematic situation with organ donation back in 1989, they called for a model where adults who were willing to donate would have "priority for receiving organs generated by the program that might be needed at a future date."

More recently, Gubernatis and Kliemt's "Solidarity Model" has also considered the idea of offering a priority to those willing to donate, or those who have already donated, as a way to cope with the rationing problem currently faced in organ transplantation.[18] They suggest that the existing medical criteria for the allocation algorithm would remain the same, but willingness to donate or previous donation should be an additional factor.

THE PROBLEM WITH PRESUMED CONSENT

Any discussion of this topic cannot proceed without considering the issue of presumed consent. Presumed consent is the model where people are presumed to have given consent for donation unless they have declared otherwise. This places the onus on the individual to make his or her organ donation wishes known—otherwise it is presumed that their wish is to be a donor. Austria, Belgium, and Spain have adopted this policy, which has been associated with increases in the number of cadaveric organ donors.[19] Erin and Harris have shown clearly that presumed consent is an affront to informed consent, appropriately labeling it a "fiction." Others have argued that presumed consent collides with the principle of autonomy.[16]

Moustarah has argued for the adoption of presumed consent in Canada.[20] However, in doing so he acknowledged that it would be a "radical change in policy." That this policy has not been adopted as of 2003, suggests that presumed consent, six years later, is still a radical policy that Canadians are not yet ready to embrace. Currently, in Ontario, families of potential donors are approached for final consent, no matter what the potential donor has indicated.[10]

The Public Cadaveric Organ Donation Program (PCODP) overcomes the ethical problems associated with presumed consent by not being presumptuous about people's wishes. In practice, this means not doing anything unless it is explicitly indicated. Thus family members would not be able to have their wishes override those of the deceased. In doing so the important principles of autonomy and the related concept of consent are retained. Respecting this, in the PCODP people are persuaded that in order to receive a personal health benefit they will have to *choose* to consent to donation upon their death.

CONCLUSION

With the introduction of PE, transplant centres are starting to accept the idea that receiving a health benefit from a donation is acceptable. Others have also argued for increased incentive to donate.[7] Kleinman and Lowy, and Gubernatis and Kliemt have both argued that those who are willing to donate should receive a priority benefit if/when a transplant becomes necessary.

The argument offered here is that the privately administered models of LRD, LUD, PE, and NDD are unjust, and that these models are undermining the public CD programme. Consequently the cadaveric donation programme should be rebuilt. This rebuilt programme would be called the Publicly Administered Cadaveric Donation Model.

By building on the concept of ethically acceptable, nonfinancially based incentives to donate, and the equitable nature of a public programme like CD, I have argued for the application of the moral principle ''if you give (organs) you shall receive (organs)'' within the framework/algorithm of the existing publicly administered CD programme. If adopted, the PCODP could reinvigorate the existing CD programme, and may overcome public apathy towards it by finally giving the general public a compelling reason to donate. This proposal would of course be a solution aimed at the long term and would take time to research, develop, and implement.

Author's affiliation
Mr S Giles, Toronto General Hospital, University Health Network, 200 Elizabeth Street, Room ESG-470, Toronto, ON, Canada M5G 2C4
stephen.giles@uhn.on.ca

Received 2 January 2003
In revised form 30 June 2003
Accepted for publication 4 September 2003

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Building the Bridge:
Social Workers Are Needed for Transitional Work with Pediatric Renal Patients

By Caroline Jennette, MSW, and Maria Ferris, MPH, MD, UNC, Kidney Center, Chapel Hill, NC

Recent communications with some pediatric-onset renal disease patients who are now under the care of internal medicine care providers have provided the following frustrations and discouragements about the transition from childhood to adulthood:

> "I think that doctors do not do enough to prepare you for the realities of adulthood. I have been engaged for over three years and cannot get married because of insurance. Because of the enormous cost of my medical bills I have had to continue on my father's insurance. I cannot afford to do anything else. I am 26 years old, cannot work, go to school or get married because of this disease. It has taken every part of what should be a normal life."
>
> "At the age of 15, I grew up fast learning that I would most likely only live to the age of 30; half my life was over. Emotional support was essential to my survival through high school and even now."
>
> "My disease was very difficult for me to understand, even as a college student. Liaisons that could have helped me to better understand my disease, what it meant to me, and how it would affect my life would have been invaluable"
>
> "Whatever anybody thinks, any kind of help would improve transitions."

The above quotes reflect the many psychosocial and societal issues children and young adults have as they grow up with chronic kidney disease. New technologies and better preventive care for both adults and children with chronic diseases have significantly prolonged life expectancy, meaning that more individuals are making the transition from childhood to adulthood with pediatric-onset diseases. Based on United States Renal Data System data, the vast majority of adolescents with chronic kidney disease (CKD) are expected to survive into adulthood, with a 10-year survival rate for transplant recipients of 85.6% and for those on dialysis of 66.9%.[1] With this expectation for patient survival, the period of transition from traditional, pediatric-focused medical care model to an adult-oriented, self-management care model requires specific attention. Beyond medical management, these adolescents and young adults are expected to transition to employment, to insurability independent of the parents, and hopefully to a living environment independent of their parents. This transitional phase is clearly a complex process, and failure to transition smoothly can result in serious consequences.

Recent national interest targets this transition for children with chronic medical conditions. In kidney disease populations, it is not clear how adolescents with chronic kidney disease (CKD) navigate the complex pathway to independence. Traditional, prospective registries of children and adolescents with CKD stop data collection at age 18 and, in many cases, issues of disease self-management, insurance, employment and housing are not assessed. Of 43 manuscripts focusing on transition published between 1982 and 2003, only one was based on a kidney disease population.[2] This study was composed of primarily Caucasian kidney transplant survivors in the Midwestern United States.[3] In all disease categories, the most frequently cited criteria for transfer to internal medicine medical care was age over 16 years, which is an arbitrary means for assessing transition readiness. In terms of program implementation for transitional patients, a meta-analysis of transitional programs for adolescents with a variety of chronic diseases found that the majority of research that has been done is exploratory in nature and lacking in measured outcomes.[2]

Helping teenagers and young adults begin to navigate their way through the adult health care system is beneficial, but there are not research results showing which programs work best and can be reproduced effectively. Optimal preparation, timing and methods in support of transition to self-management are all unanswered questions. Outcome measurements of existing or new programs must take place in order to create valid and reliable "best practice" models for transition services, which are sorely needed to enhance social work research and practice. Renal social workers have the opportunity and the responsibility to participate in the development of evidence-based models for transitional care to strengthen and measure outcomes of these programs and to contribute rigorous, evidence-based research in the field of social work.

Social workers have a unique position in the world of transitional patient care, as the core concepts listed in the NASW code of ethics deal with strengthening relationships and respecting a client's autonomy and self-determination. Children with chronic illnesses like kidney disease need these tools of empowerment much more than normally developing children, as their path to adulthood is often strewn with more obstacles and pitfalls. Social workers who deal with renal patients can help make sure an adolescent patient's voice is heard as they begin to enter the world of adult medical care.

Formal links between pediatric and adult health care systems have been identified as key components for a smooth transition.[4] Families may also need assistance, particularly the parents in "letting go" and helping their child become more independent. Social workers have the ability to act as a "bridge" between youth and families and between adult and pediatric providers to ensure that the patient's rights and autonomy don't get lost in the shuffle. Psychosocial services to assist with referrals to health insurance agencies, education, training, employment, rehabilitation, and community resources in a developmentally-appropriate fashion, are additional components to optimal transitions that social workers are trained to provide.[5,6] Further work and research in this area is needed.

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Social Workers Explore Possible Risk Factors for Depression in New Hemodialysis Patients

Laura Root, MSW, LCSW, Saint Alphonsus Nephrology Center, Boise, ID

BACKGROUND RESEARCH AND LITERATURE REVIEW

Beginning in 1976 (Federal Register, 1976), when social workers became a mandated part of the renal team, nephrology social workers have been looking at ways to improve assessment and intervention provided to End Stage Renal Disease (ESRD) patients. Maximizing patients' functioning and overall well-being have become priorities for nephrology social workers who work in dialysis settings (Kutner, Curtin, Oberly, & Sacksteder, 1997). Research suggests that level of depression is associated with increased risks of mortality and hospitalization is ESRD patients who are maintained on hemodialysis (Lopes et al, 2002). Other research indicates that although little is known about depression in new dialysis patients, depressive symptoms are very common (Watnick, et al, 2003). In recent research conducted, depression among dialysis patients was significantly associated with lower quality of life and Caucasian race (Watnick, et al, 2003). If other patient characteristics could be linked to depression, this would allow social workers to quickly determine which new dialysis patients are at higher risk for developing it.

One nephrology journal forecasts a growth rate of 7.1% for dialysis patients in the United States to the year 2010 (Xue, Ma, Louis, & Collins, 2001). Unfortunately, as the number of patients in dialysis facilities continues to grow, many social workers have found themselves placed in the role of financial counselor and transportation expert. There is a trend among forward-minded nephrology social workers to educate department heads and facility directors that this is not the most efficient use of Medicare dollars (King, 2003). This vision calls for an expansion of nephrology social workers' ability to function in their intended role, namely, providing psychological counseling and emotional support to patients and families (King, 2003). Because depression in hemodialysis patients is common and potentially life threatening, it is an area of particular concern to nephrology social workers. While nephrology social workers struggle to find the time to adequately meet the emotional needs of their patients, it would be helpful to know of certain patient characteristics (risk factors) which place new hemodialysis patients at higher risk for depression. This would enable the social worker to more quickly assess and provide needed intervention.

The literature review revealed associations between depression and gender, age, ethnicity, level of education, medical insurance, perceived health and perceived stress (Segrist; Mollaoglu, 2004; Thomas et al, 2003; Lesser et al, 2005; L.A. Health, 2001; Rintala et al, 2005). The purpose of this project is to examine the prevalence of depression in new hemodialysis patients and to explore the interrelationship of these psychosocial and demographic factors and how they relate to the level of depression in these patients. These variables were chosen because of the cited connections to depression in our research and because of the relative ease with which information on these variables can be obtained. One aim of this study was to be able to quickly identify which new hemodialysis patients may be at higher risk for depression. Therefore, the variables used must, again, be information that is fairly easy to obtain. It is our hope that, as a result of this study, nephrology social workers will have an expanded ability to detect factors which could place a new dialysis patient at higher risk for depression.

HYPOTHESES

This study examined the prevalence of depression symptoms in new hemodialysis patients and the interrelationship between depression and eight patient demographic and psychosocial variables.

Hypothesis 1: A lower level of formal education is associated with higher levels of depression in new hemodialysis patients.

Hypothesis 2: The absence of medical insurance is associated with higher levels of depression in new hemodialysis patients.

Hypothesis 3: A lower level of perception of their own lifetime health is associated with higher levels of depression in new hemodialysis patients.

Hypothesis 4: A higher level of patient-perceived stress related to dialysis is associated with higher levels of depression in new hemodialysis patients.

METHODOLOGY

This study focused on new hemodialysis patients who receive dialysis treatment from one of the six Saint Alphonsus Nephrology Center facilities. Five of the six facilities are located in the state of Idaho and comprise five of the seven total dialysis facilities within the state of Idaho to date. The sixth facility in the study is located in Ontario, OR, 15 minutes across the Idaho border. All facilities in this study are located in rural areas. The Boise facility is located in the largest and least rural area with a population of less than 200,000. All newly admitted hemodialysis patients (three months or less on dialysis) age 18 and over who were capable of giving informed consent and who were able to complete without assistance the Beck Depression Inventory-Fast Screen for medical patients were eligible for the study. Out of convenience and continuity, those patients not able to complete the BDI-Fast Screen due to language, literacy, visual or mobility barriers were not included in the study.

We used the Beck Depression Inventory-Fast Screen for medical patients to assess the patients' levels of depression. The BDI-Fast Screen is a seven-item self-report instrument that screens for depression in adolescents and adults. It consists of seven items extracted from the 21-item Beck Depression Inventory-II (Beck, Steer, & Brown, 1996). The BDI-Fast Screen measures the severity of depression that corresponds to the psychological or nonsomatic criteria for diagnosing major depression disorders as listed in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV; American Psychiatric Association, 1994). It was specifically developed for evaluation of symptoms of depression in patients reporting somatic and behavioral symptoms that may be attributable to biological and medical problems (Beck, et al., 2000). We chose this instrument because the BDI-Fast Screen for medical patients has a high validity and reliability score; it was specifically developed for medical patients; it can be easily completed; and because it was found to be positively correlated with the diagnosis of a DSM-IV mood disorder (Beck et al., 1997; Cicchetti, 1994).

For the administration of the BDI-Fast Screen, we decided to have workers who were unfamiliar with the patients administer the BDI-Fast Screen. By doing this we hoped to maintain confidentiality and establish uniformity of administration. There was concern that patients might want to use that time with their social worker to discuss other unrelated issues or would be reluctant to provide honest answers to the questionnaire to someone they know. The patients were asked individually whether or not they would like their BDI-Fast Screen scores to be given to their social worker. Two social workers and one peritoneal dialysis nurse conducted the surveys during the patients' dialysis treatment time. Again, we chose this time to maintain similarity of circumstance and environment for the patients during the survey. The social workers conducted the surveys in the Boise, Nampa, Twin Falls, Burley, and Ontario facilities. Due to the distance of the Pocatello facility, and travel to that facility not being cost effective, a peritoneal dialysis nurse conducted the surveys in that facility.

All surveys were initiated using a scripted introduction and a request for participation. At that time, patients were given information regarding the nature of the research; the time it would take to complete the survey; and the monetary incentive of $10 they would receive upon completion of the survey. Interested patients signed a consent form, completed the BDI-Fast Screen, and completed an eight-item questionnaire to obtain information concerning their ethnicity, years of education, age, sex, medical insurance status, time in months they had to prepare before starting dialysis, lifetime health and stress level related to their dialysis experience (Appendix A). They were then informed of their BDI-Fast Screen score and the level of depression it indicated. They were then given the option of having the surveyor pass that information on to their social worker for further assessment, education, and intervention. Patients were then given the monetary incentive and asked to sign a form stating they received the money. The results of the questionnaire and BDI-Fast Screen were then correlated to identify possible related factors to patients' depression levels.

RESULTS

Seventy patients completed both the questionnaire and the BDI. The results of the questionnaire and BDI are shown in **Table 1**.

Table 1. Results of Questionnaire and BDI

n = 70 **Ethnicity**	n	%
White	60	85.7%
Hispanic	5	7.1%
Native American	5	7.1%
Black	0	0.0%
Other	0	0.0%
Average Years of Education: 12.42		
Average Age: 63.48		
Sex	n	%
Male	39	55.7%
Female	31	44.3%
Medical Insurance	n	%
Insured when dialysis started	63	90.0%
Not insured when dialysis started	7	10.0%
Average time in months between learning of the need and starting dialysis: 10.97		
Average lifetime health score: 7.15		
Average dialysis stress score: 5.79		
BDI Score Ranges	n	%
Minimal	23	32.9%
Mild	42	60.0%
Moderate	3	4.3%
Severe	2	2.9%
Average BDI Score: 3.63		

Based on the sample size, no tests of significance were run for Ethnicity, or Medical Insurance Status. It was found that, in the sample, there was no significant relationship between sex (r^2=.054; p=.329; n=70), age (r^2=-.192; p=.053; n=70), or time in months to prepare for dialysis (r^2=-.082; p=.25; n=70). There was a significant negative relationship between how a person rated their lifetime health and their depression levels (r^2=-.338; p=.002; n=70). There was a significant positive relationship between how stressful a person rated their dialysis experience and their depression levels (r^2=.455; p=.000; n=70). There was also a significant interaction effect: lower health ratings coupled with higher stress ratings significantly increased the depression scores (r^2=.244; p=.021; n=70).

DISCUSSION

The average BDI-Fast Screen score in this study was 3.63, indicating that one-third of the respondents fell into the category "minimal symptoms of depression" (*BDI Manual*, 2000). Though the remaining two-thirds did have some level of depression, 60% of those fell into the "mild symptoms of depression" category (BDI manual, 2000), leaving only 7% of patients experiencing moderate or severe levels of depression.

These results echo other studies that concluded that depression symptoms in new hemodialysis patients are very common (Watnick et al, 2003). The percentage of patients with depression symptoms in other studies ranges anywhere from 25%–62% (NKF KDOQI, Mollaoglu, 2004). Depression rates of 30%–50% have been reported in dialysis patients who use self-reported measures of depressive symptoms (NKF KDOQI). What is not known from these past studies is the level of depression found (mild, moderate, severe). Overall, it appears that estimates of the prevalence of depression in new hemodialysis patients have varied substantially, depending on differences in methods and criteria used to define depression.

This study examined eight psychosocial and demographic items to see how they correlate with depression symptoms. Of the eight, only two are statistically significant. First, there was a significant negative relationship between how the respondents rated their lifetime health and their depression level. Those who rated their lifetime health as being overall "fairly healthy" typically seem to have more positive attitudes in general, possibly leading to lower depression levels. Likewise, those who rated themselves as having poor lifetime health seemed to have a tendency to see many things in "the glass is half empty" manner in general, thus leading possibly to higher levels of depression.

Second, there was also a significant positive relationship between how stressful the respondents rated their dialysis experience and their level of depression. This mirrors a 2005 study by Rintala et al in which stress was found to be related positively to depressive symptomatology. A study by Rubin et al in 1993 gives one possible physiological explanation of this. According to their research, "if stress continues and a person is unable to cope, there is likely to be a breakdown of bodily resources. It is in this stage that there may be a reduction of the levels of epinephrine and norepinephrine in the brain, a state related to depression" (Rubin, Paplau, & Salovey, 1993).

In this study, responses to these two questions, "on a scale of 1–10 rate your lifetime health" and "rate the level of stress you have felt in starting dialysis," were found to be linked to levels of depression in new hemodialysis patients, especially when used together. Lower health ratings coupled with higher stress ratings significantly increased the depression score. Based on these findings, asking new hemodialysis patients these two questions may prove valuable in early assessment of their risk for developing depression.

Depression is a major health risk for hemodialysis patients. It is linked to increased mortality and hospitalizations (Peterson et al, Goodkin et al). If left untreated, it may worsen over time and lead to unwanted outcomes. Even mild levels of depression should be promptly addressed and treated to curtail the possible negative impacts on patients' lives. These study findings provide a foundation upon which social workers can build to maximize positive patient outcomes through early risk assessment for depression.

LIMITATIONS OF FINDINGS

Several limitations of this study should be noted. The small number of participants in some of the groups (ethnicity, uninsured) made it impossible to achieve statistical significance. Larger studies in these areas will need to be conducted before generalizations can be made.

There is also concern regarding the degree to which the study sample is representative. For instance, new dialysis patients unable to independently complete the BDI-Fast Screen due to language, literacy, visual, or mobility barriers were not included in this study. Typical dialysis populations *do* include patients who do not speak or read English or who have visual or mobility impairments. Therefore, the sample in our study is not completely representative of the typical dialysis population. Also, our sample included only participants from one part of the country. Therefore, social workers should use caution when generalizing these findings to other regions.

Additionally, several patients (n = 10, 12%) who were asked to participate in the study declined to do so for unknown reasons. This excluded a significant number of potential participants from the study.

Another important limitation to this study is the reliance on self-reporting to determine depression levels. Although the validity of this particular self-report questionnaire is high, like other self-report assessments, it cannot be validated at 100%.

SUMMARY

This investigation explored the relationship between depression and gender, age, level of education, ethnicity, medical insurance, perceived health, perceived stress, and amount of time patients knew dialysis treatment would begin prior to their first treatment. The following is a summary of findings for each of the four research hypotheses tested in this study:

Hypothesis 1 (not supported). There was no significant relationship between depression and a lower level of education in new hemodialysis patients.

Hypothesis 2 (not supported). There was no significant relationship between depression and absence of medical insurance in new hemodialysis patients.

Hypothesis 3 (supported). A lower level of perceived lifetime health is associated with higher levels of depression in new hemodialysis patients.

Hypothesis 4 (supported). A higher level of perceived stress related to starting dialysis is associated with higher levels of depression in new hemodialysis patients.

Thanks to Diane Thompson for help with conducting patient surveys and to Amanda Love for assistance with statistical analysis.

Note: *This study was funded by the NKF-CNSW.*

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Appendix A

QUESTIONNAIRE

First four questions to be completed by interviewer

1. Circle which one below best describes your ethnicity:

   White
   Hispanic
   Native American
   Black
   Other

2. How many years of education have you had? (please circle)

   1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 20+

3. Did you have medical insurance when you started dialysis? ☐ Yes ☐ No

4. How many months before starting dialysis did you know you were going to start dialysis? (please circle)

   1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 30 36 42 48 54 60 60+

Next two questions to be completed by the patient

5. On a scale of 1–10 (1=unhealthy, 10= very healthy) how would you rate your health during your lifetime? (please circle)

   1 2 3 4 5 6 7 8 9 10
   Unhealthy Very healthy

6. On a scale of 1–10 (1= not stressful, 10= very stressful) how stressful has it been for you to start dialysis? (please circle)

   1 2 3 4 5 6 7 8 9 10
   Not stressful Very stressful

Using Patient Focus Groups to Respond to Patient Satisfaction Surveys

Wendy Funk Schrag, LMSW, ACSW, Renal Care Group Patient Services Manager, Newton, KS

Every year, Renal Care Group (RCG) asks patients on their satisfaction survey if they are satisfied with how involved they feel in decisions about their care. According to the company that scores our surveys, this question has shown to be the top predictor in patient satisfaction for home patients and second only to patient safety for hemodialysis patients. In 2004, this question was identified as an area for improvement on the RCG survey results. While the survey results provide quantitative data, they do not provide patient perspectives which could prove valuable in determining methods to use to help patients feel more involved in decisions about their care. It was determined that patient focus groups would be a way to include patients' perspectives in determining areas for quality improvement. Focus groups are informal with members who have like interests or ideas (Nielsen, 1997; Morgan, 1997). Focus groups usually have 6–12 members and generally last 90 minutes to two hours. Members are recruited ahead of time and told the basic purpose of the group. Focus groups require moderators who are trained in group dynamics (Morgan). Because social workers receive training in group work, it was decided that members of the RCG Social Work Advisory Board would conduct the patient focus groups. Because the focus groups were facilitated by more than one moderator, it was important to create a standardized patient focus group process.

GENERAL FOCUS GROUP PROCESS

Regardless of the topic, focus groups follow a general procedure:

Preparing for the Focus Group

1. Identify the major objective of the meeting.
2. Carefully develop five to six discussion questions (moving from general to specific, less personal to more personal).
3. Plan the session (scheduling, room, refreshments, ground rules, agenda, how the information will be recorded).
4. Invite members to the meeting.

Facilitating the Session

1. Introductions
2. Explain the means to record the session.
4. Carry out the agenda.
5. Facilitate discussion of questions, ensuring as even participation by group members as possible.
6. Close the session.

Immediately After the Session

1. Make any additional notes from group session notes.
2. Write down any observations made during the session (McNamara, 1999).

THE RENAL CARE GROUP FOCUS GROUP PROCESS

Following the general focus group outline, the social workers received specific instructions for conducting their focus groups. Consultation with a renal dietitian was also made to provide renal-appropriate refreshments. The general outline of the RCG patient focus group meetings was as follows:

1. Welcomed group members; assisted with nametags and obtaining refreshments.
2. The social workers then gave the following introduction: "Each year in April, Renal Care Group conducts patient satisfaction surveys. One question on the survey asks you to tell us how satisfied you are with how involved you are in decisions about your care. We're here today to discuss this item and any ideas you may have on how we as a company can work to improve in this area. We'll start today's meeting by having each of you tell the group three things: (1) Your name. (2) On a scale of 1-4, if 4 is the most satisfied, how satisfied are you with how involved you are in decisions about your care? (3) Any example you can give of how you feel you have been involved with decisions about your care. If you are a family member, you can answer this question from your point of view. Throughout the meeting, you may see me making some notes. I will not be including your names, and we will be combining your suggestions with those of other patient focus groups that are happening throughout Renal Care Group."
3. The social workers made tallies of how each patient and family member answered the scale. They took notes of examples patients and family members gave of how they have been involved in decisions about their care.
4. Then the social workers explained: "We are now going to spend the rest of the time listening to some more of your ideas about how

patients can be involved in decisions about their care. What are some more ideas that haven't been mentioned already?" Social workers were encouraged to only give suggested ideas if the group got stumped and had only generated a few responses.

5. Once there were no more suggestions given, the social workers thanked the group for their time and ended the meeting.

Each of the social workers also received the following form for recording their focus group:

1. Date of Meeting:
2. Person Facilitating Meeting:
3. RCG Clinic Name:
4. RCG Region Name:
5. # of patients in attendance:
6. # of family members in attendance:
7. On a scale of 1–4 (4 being most satisfied), how satisfied are you with how involved you are in decisions about your care? (Tally responses below.)
    a. 1 =
    b. 2 =
    c. 3 =
    d. 4 =
8. . List ideas/responses patients give on how to increase patients' involvement in decisions about their care:

RENAL CARE GROUP PATIENT FOCUS GROUP RESULTS

A total of 66 patients and 22 family members participated in 11 focus groups across Renal Care Group. Ten of the groups were with hemodialysis patients and family members, and one group was with peritoneal dialysis patients and family members. The mean of their satisfaction for the question "How satisfied are you with how involved you are in decisions about your care?" was 3.38 on a scale of 1–4, with 4 being the most satisfied. The mean from the in-center RCG 2004 hemodialysis survey for this same question was 3.28. For the home dialysis patients, the mean was 3.66.

A variety of suggestions for helping patients to feel more involved in decisions about their care were received from the focus groups, but these were the ones that were mentioned most often (in 4 out of the 11 groups):

✔ S*taff attitudes*: Staff can contribute to patients feeling more involved in decisions about their care by having a positive attitude, being willing to listen and answer questions, and informing patients of any changes being made to their dialysis treatment and educating them about those changes.

✔ *Physician/Nurse Practitioner visits:* Doctor and nurse practitioner visits were identified as important and appreciated by patients. Patients indicated they would like help in knowing how to better prepare for their doctor visits.

✔ *Patient education*: Patient education in a variety of forms helps patients and families understand more about their dialysis treatment, which in turn helps them participate in decisions. Patients appreciate bulletin boards, brochure displays, patient/family meetings, newsletters such as the RCG *Caring Connections*, NKF's *Family Focus*, and other types of education provided by the dialysis staff. They especially mentioned dietitian visits as helpful in learning about their treatment through monthly lab reviews.

✔ *Care plan process*: The care plan review was an opportunity for patients to see the larger picture. Patients would like to be more involved in the formation and review of their care plans.

Areas that were mentioned by at least three groups were:

✔ Staff training: Patients indicated they would like to be more involved in telling staff where to stick their access and would like more training for staff in this area.

✔ Staff tolerance: Patients would like staff to respect decisions patients make after being informed about their options instead of feeling "punished" for their decisions.

✔ Patient education: Additional areas of education mentioned were pre-dialysis education, patient/family meetings and community education.

✔ Medications: Patients indicated they would like more education about their medications so they have a greater understanding of their medications and what they do.

Patients and family members as well as the social workers expressed appreciation for the focus group experience. Patients and family members expressed gratitude for being able to express their ideas and perspectives. Social workers remarked that it was a positive process and in some instances led to some changes in their clinic processes. The first set of results (4 out of 11 groups) was shared with all RCG associates in the March/April 2005 newsletter. RCG associates are encouraged to review the results and determine if there is an area they can work on for improvement in encouraging patients to feel more involved in decisions about their care.

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Outcomes-Driven Social Work: Repackaging the Wheel

Allison Widmann, LCSW-C, MSW, MPP, Focus on Health Care and Human Services Policy, Oakton, VA

One cannot be a social worker today, particularly in nephrology, without exposure to—often—the concept of outcomes-driven social work. As noted by Johnstone (2003, as cited in Root et al., 2005), key principles of outcomes-driven social work are "launch it, measure it, report it." As presented at the National Kidney Foundation 2005 Spring Clinical Meetings' all-day workshop, "Nephrology Social Work: An Outcomes-Driven Practice Model," outcomes-driven social work has both a micro- and a macro- impact on social work interventions. It serves to enhance the level of service social workers—in this case, nephrology social workers (NSWs)—provide, as compared to the "linear model of nephrology social work practice" focusing primarily on TTI [travel, transportation, insurance] (NKF 2005 Spring Clinical Meetings).

Outcomes-driven social work is certainly a deviation from the linear model, though not in a manner that is new to the social work community. In actuality, master's-level social workers have been performing outcomes-driven social work long before the catch phrase "outcomes-driven social work" was marketed. Indeed, master's-level social workers were performing outcomes-driven social work as graduate students, and were required to do so in order to receive a MSW. The development of outcomes-driven social work is not a reinvention of the wheel. However, it clearly repackages the wheel in a manner that appears to resonate with social workers who have lost sight of the contributions they can make within their home or host setting.

Outcomes-driven social work hinges on performing well thought-out and methodologically sound research that serves a clinical, or at least clearly documented, purpose. It encourages social workers to move away from traditional direct service to analysis and assessment of the full scope of services where they can have either a tangible (financial/medical) or intangible (psychoeducational/psychotherapeutic) contribution to their setting. But is this really a new, novel approach to the involvement of social workers in their setting?

No. As previously noted, all master's-level social work students (intending to graduate from Council on Social Work Education (CSWE)-approved schools) are required to complete two semesters of research. In these classes, the aspiring social worker is expected to conduct research, sometimes on a small scale, other times on a much larger scale as part of a graduation research practicum. This research has to be conducted in the social work arena, though research requirements vary by school. However, to graduate, one must produce tangible research documents, demonstrating the capacity to "launch it, measure it, report it" using data from social work settings and incorporating analytical techniques appropriate to social work data. Is this not what outcomes-driven social work is all about?

Since social workers have been trained in outcomes-driven social work for years, why has the outcomes-driven movement acquired such momentum now? Repackaging services in such a way that they appear more "quantitative" than "qualitative" appeals to unit or agency managers who respond to raw data rather than raw feelings. By presenting a project plan that can quantitatively demonstrate the success of a particular intervention, social workers (particularly NSWs) can capture the attention of numbers-oriented facility administrators or clinical coordinators, most notably if the intervention can impact DQI scores. Quite simply, most administrators within a dialysis unit do not think of social workers as "number crunchers," and do not think to include social workers as part of the research team looking to improve the DQI scores. Presenting a task from an outcomes-driven perspective helps lend credibility to nephrology social work and, as such, can help expand the role of the NSW beyond TTI to include a broad array of services and interventions offered to patients.

In reality, however, many NSWs have been involved in monitored interventions for years. Perhaps it took the development of the concept of outcomes-driven social work for us, the social work community, to let go of our own linear mindsets and remember what we learned years ago about evaluative social work and its importance to the host setting. It is with this understanding that outcomes-driven social work will be incorporated into our daily routines. Understanding outcomes-driven social work does not always need to take workshops, seminars, or specialized training—it could be as simple as just dusting off that research methodologies textbook from years ago.

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Awakening the Advocacy/Education Role of Nephrology Social Workers: The Case of the Socioeconomic And Racial Disparity in Transplant Evaluations

William A. Wolfe, MSW

Prior to the passage of the Social Security Amendment of 1972 (Public Law 92-603), which created the End-Stage Renal Disease (ESRD) Program, there was no financial guarantee that individuals with irreversible kidney failure would have access to life-sustaining hemodialysis. Around the United States, groups referred to as "Medical Advisory" (Pendras & Erickson, 1966, p. 293) and "Life or Death" committees (Weisse, 1991, p. 101) met to decide which patients would get treatment and who would be allowed to die (Alexander, 1962; Retan, Lewis, 1966; Fox & Swazey, 1974). Among the criteria used by these committees to select patients were their income, marital status and "social worth" (Evans, Blagg, & Bryan, 1981, p. 487). One of the driving motives behind the creation of the ESRD program was the desire to eliminate this moral and ethical quagmire and thus insure that all patients have equal access to all treatment options, including transplantation (Rettig, 1980).

Unfortunately, research over the last 15 years has repeatedly documented that not all patients have equal access to all treatment options. More specifically, it is found that low-income and African-American patients are less frequently referred for transplantation evaluations (Kjellstrand, 1988; Soucie, Neylan, & McClellan, 1992; Eggers, 1995; Delano, Macey & Friedman, 1997; Institute of Medicine, 1999; Epstein, Ayanian, Keogh, Noonan, Armistead, Cleary, et al., 2000; Furth, Garg, Nev, Hwang, Fivush, & Powe, 2000; Wolfe, Ashby, Milford, Bloombergen, Agodoa, Held, et al., 2000; Epstein, & Ayanian, 2001; Alexander & Sehgal, 2002; Srikaneswaran, 2003; Lurie, 2004).

A number of factors have been cited as possibly contributing to the socioeconomic and racial disparities in this area of health care. For example, some investigators (Held, Pauley, Bovbjerg, Newmann, & Salvatierra, 1988) have referred to the existence of a "strong financial incentive" (p. 2598) in large dialysis units not to refer patients because the cost per patient falls as the size of the unit increases. Giving some credence to this explanation, other researchers (Garg, Frick, Diener-West, & Powe, 1999) have documented a strong association between for-profit units and patients having a 26% less chance of being referred for a transplant evaluation. Most recently, evidence has been increasingly pointing to inadequacy of educational information and a lack of emotional encouragement, as major contributing factors in the disparities. For example, utilizing a stratified random sample of patients, a group of investigators (Ayanian, Cleary, Weissman, & Epstein, 1999) found that African-Americans were less likely than white dialysis patients to report that their nephrologists had provided all the medical information they desired, and also that the possibility of receiving a kidney from a family member had been discussed with them. Evidence that African-American patients are less likely to be emotionally encouraged was also documented by these investigators (Ayanian et al., 1999) who found that 75.3% of white women were encouraged by their physician to consider transplantation, compared to only 59.7% of African-American women; the corresponding percentages for white and African-American men were 77.9% and 63.4%, respectively. Reinforcing the pattern of evidence in this area, King (2000) found that 44.2% of white pre-dialysis patients had been offered the option of transplantation, compared to 33.1% of African-American pre-dialysis patients. This evidence of African-American patients not being provided adequate information, or being encouraged to consider transplantation may partially explain Alexander and Sehgal's (2001) finding that they are more likely to regress, in the steps leading to transplantation, at the step of not being able to develop a definite interest in this treatment option.

Educating Patients About Treatment Options: The Emergent Role of Nephrology Social Workers

Patient education has historically been a primary responsibility of the physician (McClellan, 1986). Over the last 30 years, other health care professionals with expertise in different areas (e.g., nurses, nutritionists, pharmacists, and social workers) have been increasingly involved in patient education (Rankin & Stallings, 2001; Snella, Trewyn, Hansen, & Bradberry, 2004; Buchanan, 2004; Bailly & DePoy, 1995). Nephrology social workers' involvement in educating ESRD patients was given impetus by the enactment of the Patient Self-Determination Act of 1991, which emphasized patient choice in every aspect of care

(Breckenridge, 1997). In the ensuing years, research shows (Grumke & King, 1994) that nephrology social workers were involved in a variety of patient education issues. Most recently, shortages in the nephrology work force have compelled increasing numbers of nephrologists to delegate additional patient education tasks to social workers and nurses (Renal Physician Association, 2000). Further research reveals that for some time now these disciplines have actually been filling an education void in providing information about treatment options. In this case, a group of investigators (Holley, Barrington, Kohn, & Hayes, 1991) earlier documented that patients identified social workers, along with nurses, as the professionals who "best disseminated information and influenced choices about information and influenced choices about dialysis modality" (p. 110). Emphasis is given to the fact that the education information on transplantation, typically provided by these professionals in a dialysis unit, is only of a preliminary nature. Being preliminary, it is an initial but critical first step in the patient education process, to be more thoroughly covered by the interdisciplinary team at a transplant center (Wolfe, 2003a).

Discussing Treatment Options at More Frequent Intervals

The Centers for Medicare and Medicaid Services, in conjunction with the End Stage Renal Disease Networks, require dialysis providers to annually review treatment options with patients and record the results on care plans. Although this mandate is ostensibly complied within 100% of the cases, disparities continue to exist regarding low-income and African-American patients being equitably referred for renal transplant evaluations. Several lines of converging evidence point to the need to discuss treatment options at more frequent intervals, and that nephrology social workers may be in one of the most strategic positions to do this. Among the reasons options need to be discussed more often is that many patients are frightened and distressed at the start of treatment and are not able to absorb initial information that may be provided. Secondly, the validity of the transplant status code information on patients, provided to the ESRD Networks by dialysis providers, has been questioned (Sehgal, Coffin, & Cain, 2000). As to the reasons for nephrology social workers' strategic position in discussing treatment options at more frequent intervals, it has been suggested that it results from: (a) their day-to-day problem-solving involvement with patients and the spontaneous opportunities this presents for reproaching the subject; (b) the qualitative difference in their interactions with patients, which allows for a better sensitivity to timing and the readiness to learn; and (c) nephrology social workers may be more readily able to see patients away from the treatment experience, given that hemodialysis can cause dysfunctions in patients' ability to process information (Wolfe, 2003b).

The Impending Crisis in Patient Education About Transplantation: The Indispensable Role of Nephrology Social Workers

Analysts are predicting that the number of individuals requiring dialysis will double by 2010 (Xue, Ma, Louis, & Collins, 2001). Studies are also projecting a serious shortage of nephrologists by that year as well (Kletke, 1997; Chevalier, 1997; Hoffart & Nissenson, 1998; Luke & Galla, 2000). Additional research is projecting that the current ratio of one nephrologist for every 40 to 60 patients will increase to one for every 120 patients by 2010 (Nissenson & Rettig, 1999). Given these impending developments and the current deficiencies in information and encouragement provided to low-income and African-American patients, it probably means that these patients' chances of being adequately informed and encouraged will be even more diminished in the near future. With this as a likely scenario, nephrology social workers, along with nurses, will have to take a much more active (and even proactive) role in educating and encouraging patients about treatment options.

CONCLUSIONS

This article has endeavored to briefly highlight some salient issues on renal transplantation currently confronting nephrology social work which are likely to become even more of a concern in the not-too-distant future. Established patterns of professional practice and research clearly show that nephrology social workers have a role to play in educating patients about treatment options. The limited research in this area suggests, however, that not all see this as an integral part of their role. This was evident in King's (2000) study of factors affecting modality selection, which found that 46.1% of patients reported receiving information about treatment options from nephrology nurses, but only 19.1% from social workers. This is unfortunate because the profession has a unique opportunity to distinguish itself in terms of helping to eliminate a socioeconomic and racial disparity in health care. Given social work's long history of advocacy and sensitivity to economic and racial inequalities (Kittredge, 1988; Solomon, 1976), practitioners should bring a special passion to this pressing issue.

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A COMMITMENT WE CAN LIVE WITH

BOOK REVIEW: The Rights of the Dying: A Companion for Life's Final Moments

David Kessler. 1998. New York, NY: Harper Collins Publisher: Harper Perennial. 204pp. $22 paperback.
ISBN: 0060929162.

Reviewed by Anne Hutchison, MSW, LISW, Renal Care Group—Boardman, Boardman, OH

David Kessler, a protégé of Elizabeth Kubler-Ross and co-author with her of *On Grief and Grieving* and *Life Lessons*, has undertaken since her death this practical book of comfort to both the dying and the people who care for them. By delineating the rights of the dying he provides us with insights into how we can be present, what to say and what to do in the face of death, towards which he maintains a kind of hopefulness. He has formulated a list of these rights after years of hospice work, hundreds of "aha" moments with the dying and their families and, perhaps, most importantly, his own experiences losing his parents and close friends. The list of rights is defended with poignant case studies.

I believe this book will affirm to renal social workers the work we do every day, since the rights (there are 17 that he lists) are in keeping with the most profound social work values, those we wear proudly in our contacts with both the living and the dying. Two of the rights, in particular, exemplify our attempts to treat each individual as a unique human being: *The right to express feelings and emotions about death in one's own way and the right to express feelings and emotions about pain in one's own way.* This reminds us of the words of Mary Rau Foster, the dialysis nurse and speaker who says simply "Patients have the right to grieve." There is no "right" or "wrong" when it comes to the feelings that patients and their loved ones may express, no "appropriate feelings." In the words of Elizabeth Kubler-Ross: "What you're feeling is what you're feeling. Don't judge it, just let it be."

To speak of "rights" implies that a person or a patient can choose to exercise such rights and that, in the act of choosing, can bring a certain amount of control to our final encounters. To those of us who are "doers," we learn that all we may be able to do is just "be" with a person. To those who may be frightened to approach such encounters, there is a list of items to help us feel we have advocated in every way possible for our patients and others we care about. To those of us who presume to know what is best for another, this book reminds us that every person is unique in living as well as dying and that this uniqueness needs to be appreciated.

In fact, all of the rights he articulates are concerned with the feelings and needs of the dying. These, then, are guidelines to help us achieve greater sensitivity and comfort when struggling with our own fears, especially with the cases we see involving persons with terminal diagnosis, perhaps with a dual diagnosis of End Stage Renal Disease and cancer; or cases where the renal patient's spouse is sicker than they are and are expected to die first; or the most common cases where dialysis patients can be expected to live out a few more years at the unit, already having experienced losses which foreshadow death. In any case, our patients may choose to talk to us about dying, or they may choose not to talk to us about dying. That is clearly their right. We are reminded to "start where the person is at." Then we are encouraged to commit ourselves to their care until the end. JNSW

THE HUMAN TAPESTRY WITHIN OUR BORDERS
BOOK REVIEW: Culture & Clinical Care

Edited by Juliene G. Lipson and Suzanne L. Dibble. 2005. San Francisco, CA: UCSF Nursing Press School of Nursing, University of California—San Francisco. 512 pp., references. $33.95, paperback. ISBN: 0-943671-22-1. Also available in e-Book format readable on PCs and Pocket PC/Win CE handhelds, $19.00.

Reviewed by Donald Prebus, LCSW, Medical Social Worker, PeaceHealth Dialysis Center, Longview, WA

Your next patient, a foreign national, is seated in the waiting room. The time for you to start an assessment is only minutes away. You know next to nothing about the part of the world she comes from…her culture…prevailing beliefs there…the health practices… Here is a very handy reference guide written for health care practitioners.

You can pick this book up, begin reading just about anywhere, and have, in the space of 12–20 pages, a number of relevant insights into the cultural background of this patient that will assist you in providing culturally-appropriate health care.

Our beliefs about the transitions that accompany health, illness, birth and death are strongly influenced by our own cultural experiences. These beliefs, in turn, affect how a patient might make use of what we health care practitioners have to offer. This book systematically describes relevant cultural practices and beliefs that impact the delivery of health care to members of these groups. Without some basic understanding of these cultures, we put the quality of the care we are about to provide at risk.

The presentation of information is systematic. The main body of the book consists of short articles written by nurses and others who are experts and often members of the groups described by each article. The format outlines the same topics throughout: cultural/ethnic identity; spiritual/religious orientation; communication—oral, written, non-verbal; activities of daily living; food practices; symptom management; birth rituals and care; developmental and sexual issues; family relationships; illness beliefs; health issues; and death rituals. The 35 groups selected for description are those with the greatest numerical representation in the U.S. population and who have had large number immigrate in the last 50 years. Also included are sections dealing with European-American and African-American cultural groups within the U.S., given that many practitioners originate from outside the country.

Each of the two editors brings to this work the experience of a long professional and academic career: Juliene Lipson, in public health and anthropology, and Suzanne Dibble, in social and behavioral sciences. Both are nurses by training and both have published extensively. This book is an expansion of an earlier work, *Beyond Boundaries.*

No doubt, our having knowledge of specific cultural/ethnic groups is highly valuable. But there's more to it than following a cookbook-like recipe. First, there is the challenge in describing, on the one hand, the common characteristics of cultural/ethnic groups and, on the other hand, the diversity within them. Still, the authors have kept the information brief enough to be easily accessible in the clinical setting. The practitioner must also take into account the individual's history—the cultural/ethic group of origin; the immigration experience; as well as gender, age, class membership, and religion, among the more important other variables.

In a short, must-read introduction, the editors lay out foundations of a method of interacting with patients that brings into focus those cultural/ethnic issues that may affect health care. Importance is given to seeking direction from the patient in a way that enhances respect and trust between patient and care giver. The ASK perspective (awareness, sensitivity and knowledge) is put forward as an alternate approach to the notion of arrived "cultural competence" by bringing attention to the process of interacting with the true expert on these matters: the patients themselves. Health care providers will make best use of the information provided in this guide as an enhancement of their ability to ASK while giving care.

Reading the chapters heightened my curiosity about the cultures/ethnic groups—so much so that I had to keep reminding myself that this is a reference guide. Because of the tight focus on health issues and the structured format of the presentation, this curiosity could not be fully satisfied. Fortunately, each author has included a list of references for further reading. JNSW

HARNESSING HOPE

BOOK REVIEW: The Anatomy of Hope: How People Prevail in the Face of Illness

Jerome Groopman, MD. 2004. New York, NY: Random House. 272 pp. $14.95, paperback.
ISBN: 0375757759.

Reviewed by Megan Prescott, MSW

Dr. Groopman's book is an important exploration of the power of hope, offering invaluable insight for anyone who works with people with chronic illness. He generously shares the experience afforded by 30 years as an oncologist, humbly exploring the fumbles and missteps that guided him toward a truer appreciation of hope's role for a person facing a life-threatening illness. His book is accessible, caring and gripping, and he details the stories of those who brought him closer to his understanding with compassion and respect. Though Groopman is a medical doctor with an approach that is unwaveringly scientific, he follows an elusive quasi-new age subject, often approached by writers who lack his experience and distinction. “Hope,” it seems, is even a difficult word to define; it is not enough to interpret it as optimism or positive thinking. As the author defines it, “hope is the elevating feeling we experience when we see-in the mind's eye—a path to a better future.” By that definition, it is a critical element of recovery in the disease process.

In Dr. Groopman's work, we benefit from a full career on cancer's sharp edge through the eyes of a physician searching for something beyond the tools and practices his discipline has mastered to kill cancer in the body. Inspired by repeated experiences that pointed at the power of hope, (and some haunting encounters with hope's void) Dr. Groopman sought the structure and function in mechanisms of the mind not yet fully understood. Though underrepresented and too often ignored, recognition of the mind-body connection is present in Western medicine. We know that too much stress is bad. The placebo effect has powerfully revealed the mind's ability to help the body heal when properly engaged. Dr. Groopman's interest in hope's anatomy lead him to other scientists probing the unknown reaches of the mind and its symbiosis with the body and healing. New long-term studies offer compelling perspectives on structures in the brain that atrophy in the absence of resilience to crisis, further disabling an individual to respond differently in the future.

Though this book reaches out to a far larger audience, it has great lessons for the nephrology social worker. For some, hope is devastated by the belief that one has lost all control over one’s fate. Unless such a person can reconnect with one’s inner power, one will not feel able to learn, and certainly not to change one’s behavior. For others, inspiration resides in other patients who have been where they are, and prevailed. No amount of encouragement from the medical establishment can do what another person in similar circumstances can to help such a person envision a brighter tomorrow. In this thoughtful book, Dr. Groopman reminds us of our purpose in our work with people with chronic illness. It points with precision toward one of our greatest challenges—the restoration and protection of hope. In the absence of hope, our patients are unable to fully engage in the treatment process, limiting their outcomes. Though our patients do not usually have the possibility of full recovery from kidney failure—as did many of Dr. Groopman's facing cancer—they must be able to look forward to a reasonable degree of mastery over their illness to allow them to reengage their work, their family, their life. When they can do this, they can become a partner in their treatment and, with hope, prevail. JNSW

CNSW ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION 2006 SPRING CLINICAL MEETINGS

HOME HEMODIALYSIS PATIENTS: WHAT ARE THEIR CHARACTERISTICS?

Mary Lou Buss, Jerenda Holloway, Dialysis Center of Lincoln, Lincoln, NE, USA

With the development of new equipment there has been an increase in the number of hemodialysis patients able to dialyze at home. The Short-Home Hemo Dialysis program was initiated in August 2003 at a Midwestern dialysis facility and has grown to 22 patients in 25 months. It is particularly attractive to the rural, working patients living in the area. These initial patients are beginning to shape an image that can be recognized as an S-HHD patient.

In comparison, S-HHD patients are 10 years younger and four times more likely to be employed than incenter and PD patients. The dialysis vintage of S-HHD patients is 36 months compared to 39.3 on incenter and 22 months with PD. More females use NxStage and males use Aksys, matching machines to body size. 75% are in rural areas and eating better (11% higher albumins). Their SF-36 mental health composite scores are consistent with incenter scores but higher than PD scores. The SF36 physical composite scores are higher than both incenter and PD scores. The most prevalent cause of ESRD in our S-HHD population is diabetes (38%), consistent with the other modalities. Using a ratio of actual to target Kt/v, S-HHD adequacy is better than PD using the Aksys machine, but both S-HHD methods are lower than incenter hemodialysis adequacies. Medicare is the primary payor for dialysis among this group and although more are employed, only 14% have employer group plans.

As this modality choice continues to increase in numbers, it will be useful to recognize appropriate candidates and plan for them.

TACKLING THE AFRICAN-AMERICAN HEALTH CRISIS VIA A PEER MENTORING CABLEVISION TALK SHOW

Eric Perry, June Swartz, Nathaniel Steed, National Kidney Foundation of Michigan, Ann Arbor, Michigan, USA.

The purpose of this project was to heighten awareness that African-Americans are 4 times more at risk for CKD than Caucasians, explore causative factors and barriers, and discuss prevention options among the local broadcast community of 90,000 households in Ann Arbor/Ypsilanti, Michigan.

We utilized the oral tradition as a means to convey the problem to the television viewer. Four dialysis and transplant African-American Peer Mentors hosted the 4 shows in which African-American experts were guests. The studio audience consisted of churches, high school and college classes, and others who asked the panel questions during the hour long show. The topics included: “Is there really an epidemic?” “What keeps us from dealing with the problem?” “Does what we eat really matter?” “How can we get healthier?”

To prepare for each topic, the Peer Mentors worked with 4 community discussion focus groups of interested African-Americans, some of whom were dialysis family members (9 times more at risk to develop CKD.)

Surveys were given to discussion group members, audiences, and the peers themselves to measure behavioral change, learning and attitude. Of the discussion group members, 94% returned the surveys and 93% made behavioral changes in diet after attending the discussion groups. 82% of the studio audience returned questionnaires and 100% said they learned about barriers to getting good health care; 90% accepted the challenges given them at the end of each show to increase fruit and vegetable intake for the week.

Because 1) discussion groups wanted to continue to meet 2) peer mentors began exercise classes, 3) viewers continue to request reruns 4) 4 dialysis units have ordered the 4 part series of video tapes to show to patients and staff (for CEUs), 5) we have been invited to continue prevention programming on cable TV, 6) the series won the Philo T Farnsworth Video Festival Award, we conclude that African Americans are very interested in preventing this health crisis, and that the oral tradition is the best vehicle for education and empowerment.

SOCIAL WORKERS EXPLORE POSSIBLE RISK FACTORS FOR DEPRESSION IN NEW HEMODIALYSIS PATIENTS

Laura Root, Saint Alphonsus Nephrology Center, Boise, ID

Depression in dialysis patients is very common. It is also potentially life threatening. Consequently, it is an area of particular concern to nephrology social workers. Given the fact that growth rates for dialysis patients are expected to continue to increase in the United States over the next several years, combined with the already large size of social work caseloads, it would be useful to have a tool to help quickly ascertain which patients might be at a higher risk for developing symptoms of depression.

This paper discusses the research into which, if any, of eight psychosocial and demographic factors correlate with higher symptoms of depression in new hemodialysis patients. The eight factors are: age, gender, level of education, ethnicity, amount of time patient had to prepare to start dialysis, presence of medical insurance, perceived lifetime health, and perceived stress level. The methodology of the study is outlined as well as the findings and a related discussion.

KNOWLEDGE AND ATTITUDINAL BARRIERS TO TRANSPLANTATION FOR DIALYSIS PATIENTS

Amy D. Waterman, Sara L. Stanley, Ann C. Barrett, Barbara H. Gradala, Emily A. Schenk, Barry A. Hong, Daniel C. Brennan, Washington University School of Medicine, Saint Louis, MO, USA

Since renal transplantation can have health and quality-of-life advantages versus remaining on dialysis, we need to understand why transplant-eligible patients are not pursuing it.

We surveyed 243 transplant-eligible dialysis patients to measure their transplant knowledge and decision-making. Of the predominantly African-American (68%) and male (56%) patients, those less likely to pursue donation were older (55 vs. 50 years, p=.003) and in poorer health (51.4% vs. 36.6%, p=.02).

Less than half of transplant-eligible dialysis patients were pursuing deceased donor (40%) or living donor (17%) transplantation. Patients not pursuing transplant were more concerned about surgical pain (21.5% vs. 5.9%, p=.001) and the disappointment they would feel if the kidney failed (33.1% vs. 18.8%, p=.01) than patients pursuing it. They were also less likely to agree that getting off dialysis (54.7% vs. 82.0%, p<.001) influenced their decision about transplant. Finally, patients not pursuing transplant were less likely to know that transplanted patients generally live longer than patients remaining on dialysis (33.8% vs. 49.0%, p=.02), that patients generally wait for a deceased donor kidney for 3-4 years (12.9% vs. 30.4%, p=.001), and that donors do not pay for donation-related costs (45.3% vs. 66.7%, p=.001) compared to patients pursuing transplant.

A majority of eligible dialysis patients not pursuing transplant have a high level of fear about the transplant surgery and a lack of awareness of important living donation benefits. Improved psychosocial education about living donation is needed to correct these misconceptions.

PREVALENCE AND PREDICTORS OF SUICIDAL IDEATION IN ESRD PATIENTS

Amy D. Waterman, Ann C. Barrett, Sara L. Stanley, Barbara H. Gradala, Karren King, Emily A. Schenk, Daniel C. Brennan, Barry A. Hong, Washington University School of Medicine, Saint Louis, MO, USA

With rates of suicide and dialysis withdrawal in ESRD patients reaching 10% nationally, understanding which patients may become suicidal can offer the opportunity for intervention through psychotherapy and medication.

We interviewed 448 transplant-eligible ESRD patients (83% on dialysis) to determine their demographics, level of suicidal ideation, perceived disease burden, health, and whether they were pursuing transplant. Patients were predominantly male (55%) and Caucasian (51%), with a mean age of 53 years (SD=12.9).

6% of ESRD patients (25/448) reported having suicidal thoughts, with one patient assessed to be in imminent risk of suicide. Compared to patients with no suicidal ideation, patients reporting suicidal ideation were more likely to be male (53% vs. 84%, p=.003) have incomes less than $20,000 (38% vs. 58%, p=.05), be very frustrated by their kidney disease (48% vs. 72%, p=.02), feel like a burden on their family (34% vs. 64%, p=.002), and report poorer health (42% vs. 72%, p=.003). Not pursuing transplant and older patient age were not associated with having higher rates of suicidal ideation.

Since underreporting of suicidal ideation is probably due to social stigma, we recommend that healthcare professionals develop a depression and suicide screening protocol. Screening patients, especially males, who express being extremely burdened by their kidney disease may be helpful in reducing the suicide rate in ESRD patients.

National Kidney Foundation
CNSW
THE COUNCIL OF NEPHROLOGY SOCIAL WORKERS

CNSW RESEARCH GRANTS PROGRAM

Purpose

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

Areas of Interest

1.) Research on psychosocial factors in CKD
2.) Clinical practice research projects focusing on social work assessment and treatment strategies
3.) Educational programs to enhance patient and family understanding of CKD treatment
4.) Pilot or demonstration projects which have broad applicability to nephrology social work

Eligibility

Grant applicants must meet the following eligibility requirements:

A. Membership in CNSW
B. Minimum of two years' nephrology social work experience (CMS Guidelines)
C. Approval of the department head or director of research facility
D. Residence in the United States or its territories
E. "Qualified social worker" as stated in ESRD Regulations

Grant Requirements

Each grant recipient is responsible for:

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

Funding

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

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

How to Apply

If you are interested in preparing a proposal, please submit a letter of intent to the CNSW Research Grants Program, National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016 by October 15, 2006. The letter of intent must include the following:

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

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

Review Schedule

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

Further Information

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