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Council of Nephrology Social Workers

The Journal of Nephrology Social Work

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- Health-Related Quality of Life Among Patients Receiving Home Dialysis Therapies
- Bringing Sanctuary to Dialysis
- Improving Health Literacy in Kidney Patients: Nephrology Social Workers as Leaders

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The Journal of
Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

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

The Council of Nephrology Social Workers of the National Kidney Foundation

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Volume 39
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CONTENTS

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

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

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- HIV/AIDS
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Please email manuscripts to: **jnsw@kidney.org**. Questions? Contact Editor Teri Browne, PHD, MSW, NSW-C by email (**browne@sc.edu**) or phone (803.777.6258).

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 research and interest 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 quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. The *Journal* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

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Conflict of Interest. The *JNSW* fully abides by the National Association of Social Workers' (NASW) Code of Ethics, [**http://www.socialworkers.org/pubs/code/code.asp**]; see clause 5.02 (a)-(p) focused on research. This portion of the code pertains to conflicts of interest, research with human participants, and informed consent. Per the code, "Social workers engaged in evaluation or research should be alert to and avoid conflicts of interest and dual relationships with participants, should inform participants when a real or potential conflict of interest arises, and should take steps to resolve the issue in a manner that makes participants' interests primary." Authors who submit manuscripts to *JNSW* must disclose potential conflicts of interest which may include, but are not limited to, grants, remuneration in payment or in kind, and relationships with employers or outside vendors. When in doubt, authors are expected to err on the side of full disclosure. Additional information about conflicts of interest may be obtained via the International Committee of Medical Journal Editors' Uniform Requirement for Manuscripts Submitted to Biomedical Journals (URMSBJ): Ethical Considerations in the Conduct and Reporting of Research [**http://www.icmje.org/ethical_4conflicts.html**].

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Manuscripts submitted to *JNSW* are peer-reviewed, with the byline removed, by at least two Editorial Board members. The review process generally takes two to three months. *JNSW* 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.

Exclusive 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 should secure all necessary clearances and approvals prior to submission. 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.*

A submitted manuscript should be accompanied by a **letter** that contains the following language and is signed by each author: "**In compliance with the 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. The author(s) must inform the editor if the manuscript is being reviewed for publication by any other journals. Once accepted for publication by the editor, the author(s) cannot make revisions to the manuscript.

TYPES OF MANUSCRIPTS BEING SOUGHT

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

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Original Research. Full manuscript format should include: introduction, method, results, and discussion of original research. The method section needs either a declaration of IRB approval or exemption. Length should usually 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 should usually not exceed six double-spaced pages.

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

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

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

MANUSCRIPT SUBMISSION PROCESS

Important Update: JNSW now has an optional MS Word template available for preparing your article. Using it will enhance the production process. To obtain this template, send an email with "Template Needed" in the subject line to **jnsw@kidney.org**.

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

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

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

Order of the Manuscript Sections

1) Title page
2) Abstract
3) Text
4) References
5) Appendices
6) Author note
7) Footnotes
8) Tables
9) Figures
10) Figure captions

Title Page. The manuscript's title page should contain the title of the manuscript and the name, degree, and current affiliation of each author. Authors are generally listed in order of their contribution to the manuscript (consult the 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.

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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.

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Authors must include a two-sentence disclosure. The author note should include this disclosure (source of funding, affiliation, credentials) and contact information: "address correspondence to" primary author.

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Figure 1. Exemplary formatting for all figure captions.

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

Reference Examples

Journal Article, Two Authors

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

Journal Article, Three to Six Authors

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

Journal Article, More Than Six Authors

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

Journal Article in Press

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

Complete Book, Edited

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

Chapter of an Edited Book

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

Article from a Journal Supplement

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

Abstract

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

Editorial

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

ACCEPTANCE PROCESS

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

- An electronic copy of the final version of the manuscript. All components of the manuscript must appear within a single word processing file, in the order listed previously. Any features that track or highlight edits should be turned off; do not forget to hit the "accept all changes" function first. Do not use automatic numbering functions, as these features will be lost during the file conversion process. Formatting such as Greek characters, italics, bold face, superscript, and subscript, may be used; however, the use of such elements must conform to the rules set forth in the APA style guide and should be applied consistently throughout the manuscript.
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Health-Related Quality of Life Among Patients Receiving Home Dialysis Therapies

Dodie M. Stein, PhD, MSW, LCSW, Indiana University Health Home Dialysis, Indianapolis, IN; Janet L. Welch, PhD, RN, FAAN, Indiana University School of Nursing, Indianapolis, IN; Michael A. Kraus, MD, Indiana University Health Home Dialysis, Indiana University School of Medicine, Indiana University Health Physicians Kidney Diseases, Indianapolis, IN; James E. Slaven, MS, MA, Department of Biostatistics, Indiana University School of Medicine, Indianapolis, IN

Little is known about the health-related quality of life (HRQOL) of patients receiving daily home hemodialysis (DHHD) or peritoneal dialysis (PD). The purposes of this study are to describe the HRQOL of these patients and examine the effect of some demographic and illness characteristics on HRQOL. A total of 114 patients from a single Midwestern unit were included. Average physical component summary (PCS) scores were lower than the general population. Both DHHD and PD patients perceived themselves as having good mental health with mental component summary (MCS) scores at or above those of the general population. These results suggest that the control and independence provided by home therapies have a positive effect on patients' outlook on life.

INTRODUCTION

Health-related quality of life (HRQOL) surveys have been used for decades to assess patients with end-stage renal disease. The vast majority of studies conducted with patients receiving in-center hemodialysis (CHD) indicate that these patients have lower physical and mental quality of life (QOL) when compared to the general population, and the physical health dimension is often lower than the psychological dimension (Guerra-Guerrero, Sanhueza-Alvarado, & Caceres-Espina, 2012; Kalantar-Zadeh, Kopple, Block, & Humphreys, 2001). More importantly, lower physical and mental QOL predict hospitalization and death (Lowrie, Curtin, LePain, & Schatell, 2003; Mapes et al., 2003) and are as powerful as serum albumin or dialysis adequacy (DeOreo, 1997; Mapes et al., 2003; Mapes et al., 2004) in predicting adverse events.

Studies from a variety of countries, often over time, have explored the quality of life of patients receiving various types of dialysis. Results have differed for both modes of peritoneal dialysis (PD), continuous ambulatory PD (CAPD) or automated PD using a cycler (APD). Some PD patients showed no major QOL differences between PD modalities over time, though the mental summary score was better for APD than CAPD patients (Michels et al., 2011). Some mental health dimensions were similar to the general population of a study's country (Bro et al., 1999), with no differences over time. However, some CAPD patients had lower physical and mental dimension scores than those of the general population of a study's country (Goller, McMahon, Rutledge, Walker, & Wood, 1997). And still, other studies showed no significant differences for either mental or physical component scales for APD and CAPD patients (Guney et al., 2010). Others reported better mental component scores, similar to those in the general population, with physical function lower than that of the general population. APD and CAPD were essentially equal for HRQOL measures in other studies (de Wit, Merkus, Krediet, & de Charro, 2001; Sunder, Kalra, Nashine, Waghmare, & Ruchi, 2008). Other researchers (Bakewell, Higgins, & Edmunds, 2002; Wu et al., 2004) suggest quality of life for PD patients may be impaired at the start of PD and worsen over time.

Several investigators compared PD patients to CHD patients. While some found no differences between the modalities for quality of life measures (Kim et al., 2013), others noted better functionality for PD patients regarding mental health (Diaz-Buxo, Lowrie, Lew, Zhang, & Lazarus, 2000; Zhang, Cheng, Zhu, Sun, & Wang, 2007). In another study, PD was associated with higher levels of both mental and physical measures (Russo et al., 2010). One recent report on patients in Singapore indicated higher symptoms of depression and poorer physical health, yet higher satisfaction with care with PD compared to CHD (Griva et al., 2014a).

Researchers have reported both reduced dialysis symptoms and improved HRQOL among those receiving short daily home hemodialysis (DHHD) (Heidenheim, Muirhead, Moist, & Lindsay, 2003; Kutner, 2004; Lindsay & Kortas, 2001). A study of one large regional dialysis center also showed improvement in overall quality of life as well as physical component scores for DHHD patients (Buss, 2008). The FREEDOM Study examined the long-term effects of DHHD on HRQOL using a number of assessment tools (Finkelstein et al., 2012) and found that physical and mental component scores improved over time (4 months to 12 months); the increase was less for mental component scores, which were similar to those of the general population. Others comparing frequent in-center (6-day per week) to 3-day per week hemodialysis concluded that more frequent dialysis improved self-reported physical health and functioning (Hall et al., 2012), but did not improve objective physical performance. Home dialysis patients scored higher

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on the physical component of quality of life, compared to CHD patients, though both scored equally well and similar to the general population on the mental component (Watanabe et al., 2014).

A better understanding of the HRQOL of home dialysis patients would assist social workers and other professional staff in developing more effective interventions to help patients improve their HRQOL. The purpose of this study was to describe results on two subscales of the KDQOL™-36: physical (PCS) and mental component scores (MCS), for both DHHD and PD patients from one large home dialysis unit in the Midwestern United States. The PCS and MCS scores were each compared to demographic and illness/disease characteristics. Specific research questions were: 1) What is the HRQOL for patients receiving home therapies (DHHD, PD) and is it different for the two treatments? 2) Does HRQOL differ for individuals receiving DHHD or PD when differentiated by demographic characteristics (age, gender, and race)? 3) Does HRQOL differ for individuals receiving DHHD or PD when differentiated by disease/illness characteristics (diabetes status, length of time on dialysis, access type, adequacy of dialysis (Kt/V), serum albumin, and frequency of hospitalization)?

METHODS

Design, Participants, and Setting

Patients receiving DHHD, CAPD, or APD were included in this retrospective descriptive study. Individuals were ineligible if they had dementia, active psychosis, or cognitive impairment; had not received care from the facility for less than three months; or were non-English speakers/readers for whom there was no native language translation or interpreter (Schatell & Witten, 2012). Patients also were excluded if they were receiving services from hospice, had severe physical disabilities that made them unable to independently complete most major activities of daily living, or had a home hemodialysis thrice-weekly regimen.

Measures

Quality of life.

The Kidney Disease Quality of Life survey (KDQOL-36) was used to measure quality of life. The KDQOL-36 is a derivation of the earlier KDQOL [dialysis version] (Hays, Kallich, Mapes, Coons, & Carter, 1994; RAND Corporation, 2000), and consists of 36 items. In this study, the embedded 12-item SF-12 (Ware, Kosinski, & Keller, 1995) was used as a generic measure of HRQOL to produce both the non-disease-related PCS and MCS scores. The scores are based on t-scores with a mean of 50 and standard deviation of 10 for those in the general population. Higher PCS and MCS scores represent better HRQOL. Validity and reliability have been reported for both the original KDQOL (dialysis version) (Hays et al., 1994) and SF-12 (Lacson, Xu, Lin, Dean, Lazarus, & Hakim, 2010; Ware et al., 1995).

Demographic and illness-related information.

Demographic information included age, gender, and race. Illness-related variables included presence of diabetes, length of time on dialysis, type of access, Kt/V, serum albumin, and frequency of hospitalization during the year. Data were retrieved from the medical record. Length of time on dialysis was calculated from the date of a patient's first training in the modality of use to the date of survey administration. Albumin levels for all patients were recorded on the month the survey was administered or within the month closest to that administration. For all but four DHHD patients, Kt/V values were recorded nearest to or 1 to 2 months prior of the survey administration date. For PD patients, Kt/V values available closest to the survey's most recent administration were recorded. However, the interim ranged from 0 to 8 months, with some labs available only after the survey's administration and others not available at all.

Procedures

The Institutional Review Board reviewed and accepted the study as meeting the criteria for exempt research. Over the course of the calendar year 2012, the KDQOL-36 survey was first administered to new patients about three months after starting dialysis training. For most new patients, the survey was completed after the patient had been home doing his/her own dialysis independently for at least a month. For those experienced and continuing home dialysis patients, the survey was administered annually. The scores used for this study represent those obtained from the patient during the 2012 calendar year.

Patients completed the survey by hand over 10 to 15 minutes, usually during a regularly scheduled monthly clinic visit. For five patients whose native languages were not English and/or whose reading or visual skills were poor, an interpreter, adult family member, or social worker read the questions and answer choices to the patient in his/her native language. Spanish was the primary language for two patients, while Chinese was one patient's only language.

Responses to the survey were entered manually into an online database, the Medical Education Institute's KDQOL-Complete subscription, to allow automatic scoring (Medical Education Institute, 2013). Data entry was double-checked for accuracy.

Data Analysis

The KDQOL-Complete analysis and report subscription program automatically calculates scores for each subscale. Data from the KDQOL-Complete were exported to an Excel spreadsheet. Data on number of months on dialysis modality, Kt/V, serum albumin, and number of hospitalizations during the year were added to the spreadsheet.

Descriptive statistics were used for demographic and illness characteristics of the sample. Data were analyzed by modality (DHHD and PD) and means, medians, and standard deviations of each group were computed and compared. For differences between modality type (DHHD vs. PD), Chi-Square tests were used for categorical variables and Student's t-tests for continuous variables. For associations of MCS and PCS scores with demographic and illness variables, analysis of variance models were used due to variables having more than two categories. All analyses were unadjusted for covariates. All analytic assumptions were verified and all analyses were performed using SAS v9.3 (SAS Institute, 2000-2012)

RESULTS

Study Sample

The KDQOL-36 survey was completed, at least once, by a total of 114 people receiving home dialysis. Fifty-two people were on PD; 62% of these received CAPD. Sixty-two patients were on daily home hemodialysis (DHHD), with 58 on short daily hemodialysis (SDHD) and 4 on extended or nocturnal daily home dialysis (NHHD). Patients ranged in age from 21 to 84 years of age with mean and median ages of 53.6 and 54.5 years, respectively. As shown in Table 1, subjects were predominantly male, equally divided by race, a third with diabetes, and most (69%) on DHHD therapy had fistulas. Mean and median lengths of time on dialysis for all patients were 31.3 and 27.3 months respectively, with a range of 2.5 to 128.9 months. For DHHD, the mean and median were 37.9 and 33.5 respectively with a range of 2.8 to 104.3 months. For PD, the mean and median were 23.4 and 15.8 respectively with a range of 2.5 to 128.9 months. Patients receiving DHHD were significantly more likely to be White ($p = .01$), receiving dialysis for a longer period of time ($p = .03$), not diabetic, and with a higher serum albumin ($p < .01$).

Findings

Overall, mean PCS scores were 39.4 and mean MCS scores were 51.9. As shown in Table 2, there were no significant differences in the PCS or MCS scores by home dialysis modality. Because of this, scores were combined into an overall home dialysis therapy score for the remaining analyses. As shown in Table 3, participants who were younger and non-White had significantly higher PCS scores. There were no significant differences in MCS scores with age, gender, or race. Participants who were diabetic and hospitalized at least once had lower PCS scores. There were no significant differences in MCS scores with presence of diabetes, time on dialysis, dialysis adequacy, or serum albumin.

DISCUSSION

This study provided valuable information about the overall HRQOL of patients receiving home dialysis and the effects of demographic and illness characteristics on their quality of life. The main findings from this study were: 1) there were no significant differences in PCS or MCS by home dialysis modality; 2) PCS scores were better in younger, non-White, non-diabetic patients who remained out of the hospital; and 3) MCS scores were similar to those in the general, non-dialysis population.

Quality of Life Results

Mean SF-12 PCS and MCS scores in the general population have been reported as 50.12 and 50.04, respectively (Ware et al., 1995). Thus, both DHHD and PD patients in this study perceived themselves as more debilitated physically than the general population. In contrast, in another study, patients receiving DHHD had improved physical- and mental-component summary scores over a 12-month period (Finkelstein et al., 2012). In that study, 9% of patients receiving DHHD had a PCS score equivalent to the general population at baseline, increasing to 21% after 12 months of treatment, suggesting more longitudinal data are needed.

Interventions that help patients change their perceptions of their physical capabilities and perceptions about their ability to engage in physical activity and activities of daily living would be helpful. Enhancing physical health and encouraging physical activity (e.g., exercise programs) need to be promoted as well (Painter, 2009). Encouraging improved physical strength, stamina, and energy would be most important for general health, as well as getting back to work.

On average, both DHHD and PD patients perceived themselves as having good mental health with scores at or above those reported decades ago for the general population (Ware et al., 1995). This finding is significant as previous QOL studies have shown that dialysis patients, in general, have lower mental health scores when compared to healthy adults (Guerra-Guerrero et al., 2012). This suggests that the control and independence provided by home therapies may have a positive effect on patients' outlook on life.

Demographic Characteristics and HRQOL

PCS scores were lower in patients who were 40 years of age and older. Other studies have shown that older (≥ 65) patients report better quality of life than younger patients on a HRQOL survey (Brown, 2015; Griva et al., 2014b), though APD results were better than those for CAPD on the KDQOL-SF (Griva et al., 2014b).

More non-Whites had better PCS scores. This is consistent with studies that show that Black hemodialysis patients have better HRQOL scores for the physical components with severe comorbid conditions, though no differences were observed between races for mild to moderate co-morbid conditions (Unruh et al., 2004). It also is contrary to another study that showed Black PD patients with no higher perceived health status and quality of life than White patients (Kutner, Zhang, & Brogan, 2005). Black CHD patients have greater survival than Whites (Feroze et al., 2011). The difference may reflect biologic "hardiness," sociocultural differences, social and spiritual support, or even lower expectations or life experiences that ameliorate negative reactions to dialysis (Kutner et al., 2005). In other words, the results in this study suggest that non-White patients may be more resilient and self-sufficient.

Table 1. Demographic and Illness Characteristics of the Sample

	DHHD ($n = 62$)	PD ($n = 52$)	All ($n = 114$)	p-value
Age (years)				ns
20–39	14 (22.6)	9 (17.3)	23 (20.2)	
40–59	26 (41.9)	21 (40.4)	47 (41.2)	
60+	22 (35.5)	22 (42.3)	44 (38.6)	
Gender				ns
Female	24 (38.7)	20 (38.5)	44 (38.6)	
Male	38 (61.3)	32 (61.5)	70 (61.4)	
Race				0.01*
White	42 (67.7)	23 (44.2)	65 (57.0)	
Other	20 (32.3)	29 (55.8)	49 (43.0)	
Diabetes				ns
No	43 (69.4)	32 (61.5)	75 (65.8)	
Yes	19 (30.7)	20 (38.5)	39 (34.2)	
Time on Dialysis (months)				0.03
0–12	13 (21.0)	24 (46.2)	37 (32.5)	
13–36	20 (32.3)	13 (25.0)	33 (29.0)	
37–48	11 (17.7)	8 (15.4)	19 (16.7)	
49+	18 (29.0)	7 (13.5)	25 (21.9)	
Access (DHHD only)				n/a
Fistula	43 (69.4)			
Graft	10 (16.1)			
Catheter	9 (14.5)			
Kt/V				ns
Low (< 1.7 PD or < 2.0 DHHD)	6 (9.7)	9 (20.9)	15 (14.3)	
High (≥ 1.7 PD or ≥ 2.0 DHHD)	56 (90.3)	34 (79.1)	90 (85.7)	
Serum Albumin				< 0.01*
Low (< 3.0g/dL)	3 (4.8)	18 (34.6)	21 (18.4)	
High (≥ 3.0g/dL)	59 (95.2)	34 (65.4)	93 (81.6)	
Hospitalizations				ns
0	34 (54.8)	25 (48.1)	59 (51.8)	
1–2	19 (30.7)	21 (40.4)	40 (35.1)	
3+	9 (14.5)	6 (11.5)	15 (13.2)	

DHHD = daily home hemodialysis; PD = peritoneal dialysis; n/a = not applicable
Values are frequency (percent) for categorical variables and mean (standard deviation); range for continuous variables. *p*-values are from Chi-Square tests for categorical variables and Student's t-test for continuous variables.

Table 2. Physical (PCS) and Mental (MCS) Component Summary Scores by Home Dialysis Modality

	PCS Score	MCS Score
DHHD (*n* = 62)		
Mean (SD)	39.9 (10.7)	52.3 (8.9)
Median	40.2	54.0
Range	15.7–59.8	29.0–64.4
Patients with scores above 50	15 (24.2%)	43 (69.4%)
PD (*n* = 52)		
Mean (SD)	38.7 (10.5)	51.5 (9.7)
Median	40.0	53.2
Range	18.2–54.0	25.7–69.0
Patients with scores above 50	9 (17.3%)	33 (63.5%)
Overall (*N* = 114)		
Mean (SD)	39.4 (10.6)	51.9 (9.2)
Median	40.2	53.9
Range	15.7–59.8	25.7–69.0
Patients with scores above 50	24 (21.1%)	76 (66.7%)
p	ns	ns

DHHD = daily home hemodialysis; PD = peritoneal dialysis
PCS = physical component summary; MCS = mental component summary

Table 3. Physical (PCS) and Mental (MCS) Component Summary Scores by Demographic and Disease/Illness Characteristics

	PCS Scores Mean (SD)	*p*	MCS Scores Mean (SD)	*p*
Age (years)				
20–39	45.37 (9.40)	0.01	52.24 (8.09)	ns
40–59	37.56 (9.86)		52.34 (8.78)	
60+	38.18 (10.94)		51.33 (10.32)	
Gender				
Female	39.75 (10.72)	ns	50.74 (10.36)	ns
Male	39.14 (10.54)		52.68 (8.41)	
Race				
White	37.50 (10.70)	0.03	52.29 (8.48)	ns
Other	41.86 (9.94)		51.46 (10.18)	
Diabetes				
No	41.35 (10.47)	0.01	52.87 (8.06)	ns
Yes	35.58 (9.80)		50.12 (11.00)	
Time on Dialysis (months)				
0–12	37.00 (10.46)	ns	52.69 (9.50)	ns
13–36	40.72 (9.80)		52.00 (8.49)	
37–48	36.49 (9.38)		51.80 (9.17)	
49+	43.30 (11.56)		50.81 (10.15)	
Kt/V				
Low (< 1.7 PD or < 2.0 HHD)	38.68 (11.25)	ns	51.13 (9.76)	ns
High (≥ 1.7 PD or ≥ 2.0 HHD)	39.84 (10.59)		52.00 (8.84)	
Serum Albumin				
Low (< 3.0g/dL)	37.62 (11.86)	ns	50.77 (10.18)	ns
High (≥ 3.0g/dL)	39.77 (10.28)		52.19 (9.02)	
Hospitalization				
0	42.95 (9.73)	≤0.01	52.00 (8.51)	ns
1–2	37.31 (10.57)		52.86 (10.14)	
3+	30.81 (7.23)		49.18 (9.42)	

p-values are from one-way ANOVA models.

Illness Characteristics and HRQOL

It was not unexpected that patients who were diabetic had lower PCS scores because diabetics often have neuropathy in their hands and/or feet, and can be limited in their activities. In this study, PCS scores were also lower in patients with repeated hospitalizations. The finding is consistent with previous findings suggesting lower PCS scores were predictive of higher risks of hospitalization (Lacson et al., 2010).

LIMITATIONS OF THE STUDY AND FUTURE RESEARCH

This was a single unit retrospective study that assessed only 2 of 5 subscales of the KDQOL-36 at one point in time. The characteristics of the sample may limit generalizability of the findings because there were slightly more non-Whites on PD and twice as many Whites on DHHD. In addition, patients on DHHD had been on dialysis longer than those receiving PD. These trends may reflect cultural or economic issues.

Many demographic, disease, and psychosocial issues were not explored: employment, financial status and stresses, etiology of kidney disease, mental health issues, family dynamics, role of the dialysis partner, kidney transplant history, or previous history of dialysis modality. Patients on dialysis, in general, may think of themselves as being “sick” and debilitated, although they engage in normal activities of daily living. Those not working and those receiving disability also may differ from those who continue to work in perceptions of their physical capabilities. It may be that these dialysis patients perceive themselves as not having the physical stamina to work either full- or part-time.

These additional demographic and psychosocial issues would be useful to explore more explicitly in future studies. In addition, future research needs to look at the other subscale scores, scores over time, and the variety of psychosocial characteristics. Finally, there are some data that suggest that anxiety, depression, and lack of ability to identify one’s own emotions are important determinants of HRQOL (Varela, Vazquez, Bolanos, & Alonso, 2011) and may need to be explored more fully in patients on home therapies.

CONCLUSIONS

Administering the HRQOL survey is required of renal social workers. Given the differences in dialysis modalities, one might expect HRQOL to differ. However, few data have been available on home therapies or how they compare. The overall goal of this study was to describe HRQOL for both DHHD and PD and compare them on selected demographic and illness characteristics. While there were limitations to the study, these results suggest that, for both modalities, control and independence as well as flexibility and autonomy may have a positive effect on patient outlook on life, despite perceptions of being more debilitated physically. These findings suggest the need for more HRQOL research among people receiving home therapies.

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Bringing Sanctuary to Dialysis

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The demands of the chronically ill elderly population, underutilization of end-of-life care in dialysis, and the projected nursing shortage will have serious implications for dialysis staff care over the next decade. Little information exists regarding the effects of emotional labor on the dialysis staff and patient outcomes, or about effective programs that can be used to specifically address compassion fatigue in the dialysis unit setting. Masters–level social workers have the necessary training to facilitate in-center programs to reduce compassion fatigue symptoms, improve staff satisfaction and patient outcomes. The following article outlines a structured intervention aimed to address effective management of emotional labor experienced among dialysis unit professionals using the trauma-informed approach of the Sanctuary Model.

"Blessed is the influence of one true, loving human soul to another."–George Eliot

BACKGROUND AND SIGNIFICANCE

The dialysis unit is unlike any other medical setting. Dialysis patients with end-stage renal disease (ESRD) represent a unique population that is distinguished by a significant burden of disease and high mortality rates (Haras, 2008). ESRD census projections for 2020 reveal significant implications for clinical practice, based on the increasing rate of diabetes, rising mortality, advances in medical technology, and the expanding aging population (USRDS, 2014). Additionally, the multiple comorbidities that often accompany ESRD will pose continuing challenges for clinical management of this population (CDC, 2010; USRDS, 2014). Effective clinical management of patients in dialysis unit settings can be achieved when best practices address both the needs of the patients and staff (Laschinger, Sabiston, & Kutszher, 1997). Renal social workers' extensive training and skills can ensure that such practices are implemented in dialysis units (Council on Social Work Education, 2008; Lowrie, Curtin, LePain, & Schatell, 2003).

An understanding of the dialysis unit and the needs of staff are essential for patient and staff satisfaction. Given the high burden of patient symptoms, attention to staff interventions that acknowledge the role of emotional trauma, such as feelings of intense fear, helplessness, and detachment associated with renal disease needed. Although little is known about emotional trauma as it specifically relates to dialysis patients, evidence suggests that, in general, chronic illness can result in physical, mental, and emotional trauma for patients (Seifter, 2010). Treatments associated with dialysis, such as multiple hospital admissions, surgeries, medications, and dialysis treatment itself, may result in depression, anger, social withdrawal, or hypervigilance (Seifter, 2010). When this occurs, dialysis staff can be greatly impacted as a result of continuous exposure to patient symptoms. Researchers suggest that healthcare providers are often particularly vulnerable to emotional and spiritual consequences, such as feeling disconnected from work that used to be meaningful, or having marked negative cognitive schemas as a result of continuous exposure to trauma and a therapeutic relationship that mandates "empathic openness" (Dunkley & Whelan, 2006; Pearlman & Mac Ian, 1995; Pearlman & Saakvitne, 1995). "Empathic openness" involves being aware of and open to the pain of others and using of appropriate and responsive emotions to attend to that pain (Pearlman, 1999). In the dialysis unit setting, nurses and technicians often share a considerable amount of time and space with patients. This unique relationship can result in feelings of dependency among patients who rely daily upon the staff to keep them alive, and can have a further impact on how staff connect with their clients and facilitate healing. Staff must often be fully present by giving deliberate and focused attention to patients, while attending to the emotional and physical needs of both patients and their families. The emotional nature of these interactions, where workers are expected to display certain feelings to satisfy organizational and professional expectations, has been termed "emotional labor" (Hochschild, 1983). This can be a deep or surface exchange. In the nursing profession, caring as a form of emotional engagement is seen as essential to practice , but is best managed through training and preparation (Bolton, 2000; Craig & Sprang, 2010; Henderson, 2001; McQueen, 2004).

In a supportive work environment, emotional labor can foster deep satisfaction, increase compassion, and build resilience in workers (Craig & Sprang, 2010; Grandey, 2000; Miller, Birkholt, Scott, & Stage, 1995). On the other hand, repeated exposure to work-related stress, without adequate support and built-in buffers, can trigger a compassion fatigue response, including short-term emotional exhaustion (Bolton, 2000; Bride, 2007; McQueen, 2004). As emotional resources are depleted, workers feel they are limited in how they care for others (St. Pierre, Buerschaper, Hofinger, & Simon, 2011). This is particularly important for human service providers whose job roles require emotional

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labor. If not addressed, compassion fatigue may lead to the long-term maladaptive response of burnout that may induce some to leave the profession, or in worse case scenarios, continue to practice in a disconnected manner (Bride, 2007). Furthermore, in dialysis settings where futility of care may occur, staff may experience vicarious traumatization, which is psychological distress that can result when staff empathically engages with their patient's individual trauma (Pearlman & Mac Ian, 1995; Sabo, 2011). The workers may begin to reassess their reality, and there may be an inner transformation that negatively colors their world-view (Pearlman & Saakvitne, 1995). Constant exposure to traumatic events, such as death, dying, and chronic illness, can have a cascading negative effect on staff, and result in what is referred to as a "Negative Tetris Effect." Achor (2010) describes this phenomenon as a pattern of thinking that focuses overwhelmingly on negative aspects of both professional and personal life. Furthermore, this "pessimistic or fault-finding view of the world can make staff more susceptible to depression, stress, poor overall health, and substance abuse" (Achor, 2010, p. 93).

Due to the complexity of the dialysis unit setting and treatment needs of clients, the well-being of nurses and dialysis staff who provide daily interventions should be adequately addressed to ensure positive outcomes for staff and clients. Coping strategies for dialysis staff and responses to patient trauma can have an impact on work-related stress (Hayes, & Bonner, 2010). If left unaddressed, poor reactions to workplace stress can lead to distress and burnout among dialysis care providers and decreased patient satisfaction (Laschinger & Leiter, 2006; Sudhaker & Gomes, 2010). This is harmful to patients, caregivers, and dialysis staff, and can be costly to the unit.

Trauma-informed interventions will be especially meaningful for dialysis staff who have continuous exposure to patients' and families' distress. A clear focus on staff needs, including adjustment and coping with the emotional and physical demands is vital for staff satisfaction, staff retention, and positive patient outcomes. Master's–level renal social workers can best provide trauma-informed interventions for dialysis staff. Graduate social work education prepares students for competent trauma-informed practice, because social workers specialize in treating trauma survivors (Council on Social Work Education, 2008). Trauma studies have gained considerable attention over the past 30 years (Abigail & Wilson, 2005; Balaev, 2008; Caruth, 1996; Herman, 1997). This era provided a base of scholarship that included investigation into the effects of chronic stress and the neurobiological consequences of emotional dysregulation (Felitti et al., 1998; Pynoos, Steinberg, & Goenian, 1997; Schore & Schore, 2008). This research provides the empirical support for clinical and organizational interventions, including the Sanctuary Model (Bloom & Farragher, 2010).

Schools of social work now incorporate trauma theory and treatment in their curricula through individual courses or trauma treatment certification programs (Breckenridge & James, 2010; Bussey, 2008; Cunningham, 2004; McDonald et al., 2007; McKenzie–Mohor, 2004). The School of Social Work at the University of Buffalo has integrated its entire MSW curriculum with a trauma-informed and human rights perspective. Although it is likely that most trauma-informed practice is found in mental health settings and with affected families and children, application of this practice to the dialysis unit setting is worthwhile given the setting and the potential consequences to patients if best practices are not consistently applied.

Following is a proposal for introducing Bloom and Farragher's (2010) trauma-informed psychoeducational intervention called Safety Emotion Management Loss and Future (SELF) into an existing hospital-based dialysis unit. SELF is one of the three core components of the Sanctuary Model. The Sanctuary Model is a therapeutic milieu that is theoretically and empirically founded on trauma theory (Bloom, 1997). This proposal will utilize a case example from the author's personal experience. It will include an overview of the dialysis setting as it relates to organizational stress, an introduction to the Sanctuary Model, and a review of SELF and how this intervention could be applied using the case example. Barriers to implementation, as well as suggestions and recommendations for ensuring sustainability and success of the model, will be included.

THE DIALYSIS UNIT

Environment

The dialysis unit setting is complex and demanding (Dermody & Bennett, 2008; McVicar, 2003). Although the dialysis unit environment and staff have an impact on patient outcomes, few studies have focused on these subjects. Research indicates that important patient outcomes (e.g., serum albumin levels and compliance with treatment) are positively correlated with patient perceptions of staff and dialysis unit characteristics (Argentero, Dell'Olivo, Santa Feretti, & Working Group on Burnout, 2008; Kaveh & Kimmel, 2001; Kimmel, 2000). More studies are needed in this important area.

Staff

Medical professionals who work in dialysis units represent a unique group who are required to balance the pervasive needs of patients with unremitting changes in healthcare (O'Brien, 2010). Although advancements in treatment contribute to the overall survival of dialysis patients, health-related quality of life (HRQOL) remains low as compared to the general population and is a predictor of risk for patient mortality and hospitalization (Fukuhara et al., 2003; Mapes et al., 2003).

Dialysis nurses and technicians must provide patient-centered care with a level of confidence and empathy that result in supportive and effective treatment in the face of these challenges. These professionals are exposed to more aspects of the patients' care than other members of the healthcare team, including moments when patients are emotionally or physically not well. For patients with physical limitations, many dialysis staff members must tend to the patients' during treatment. These tasks could be as simple as repositioning the patient, or as time-consuming as cleaning up after a bowel movement. The staff may also spend part of their time listening to patients discuss their feelings on loss and grief especially when the patients have multiple comorbidities. Many dialysis patients face multiple losses beyond their kidney function that can involve relationships, sexuality, and independence (Chilcot, Wellsted, & Farrington, 2008). Additionally, this population experiences more hospitalizations than individuals without CKD and at increasing rates as the illness advances (USRDS, 2014).

Aging Population

Although not all dialysis patients have had a past or present traumatic life event, research suggests that many dialysis patients, especially older patients with multiple comorbidities experience chronic stress and poor coping, often related to pain and discomfort (Lopes et al., 2004). Attention to the needs of older adults is particularly important as it relates to trauma-informed interventions, given the increase of this population in dialysis unit settings. Those aged 65 and older continue to represent that fastest growing number of patients with CKD and ESRD. Furthermore, compared to those without ESRD, this group has a higher risk for mortality (USRDS, 2014). In general, dialysis patients over 75 are typically diagnosed with more than 3 medical problems (Anand, Kurella Tamura, & Chertow, 2010). The addition of dialysis to the aging process results in a disease trajectory that involves frequent hospitalizations, acute physical complications, multiple comorbidities, high symptom burden, caregiver stress, and declining mental health (Swidler, 2010). Older patients experience multiple symptoms, such as pain, fatigue, insomnia, unintentional weight loss, neuropathy, and depression (Swidler, 2010).

Mental Health

As CKD and ESRD prevalence rises in this population, the incidence of functional disability, cognitive dysfunction, and depression is increasing (Swidler, 2010). The multitude of physical and psychological problems can lead to chronic stress and cumulative trauma in many adults who receive dialysis treatment. Multiple losses, combined with fear of dying and dependency upon treatment can also result in high levels of depression among this population (Davison, 2007; Kimmel, 2000; Sledge et al., 2011; Watnick, Wang, Demdura, & Ganzini, 2005; Wuerth, Finkelstein, & Finkelstein, 2005). Despite reports of high depression rates in dialysis patients, few receive treatment for their symptoms (Chilcot, Wellsted, & Farrington, 2008; Guzman & Nicassio, 2003; Sledge et al., 2011). This could potentially influence the culture of the dialysis unit setting and the relationship between dialysis patients and staff.

All of these aspects of care can create a high-stress environment for staff working in a dialysis unit setting, making the need for a supportive and safe work environment essential to ensure the well-being of both staff and patients. Safe work settings are predictable, even in fast-paced and reactive units, and employees know where to get help. Bloom and Farrangher (2010) suggest that exposure to chronic stress without adequate organizational and individual support can lead to workers to become emotionally dysregulated (have emotional responses that are poorly modulated) and feel disconnected from their work. Chronic emotional arousal can deplete emotional energy and reduce empathic concern, which is the ability to respond with warmth and compassion. This increases personal distress, which generates anxiety and discomfort from watching others suffer (St. Pierre, Buerschaper, Hofinger, & Simon, 2011). Bloom and Farragher (2010) assert that the absence of empathic concern can have an impact on the provider's ability to emotionally regulate and result in occupational dissatisfaction and burnout (Pearlman & Saakvitne, 1995). When this happens, a distressed organization can become more authoritarian in their treatment delivery and less deference is given to complex processing that creates responsive and tailored treatment for individuals and groups within the organization (Brehmer, 1992; Gary & Wood, 2011; Gigerenzer & Gaissmaier, 2011; Wood & Bandura, 1989). Trauma-informed education and training programs provided by licensed renal social workers can help prevent occupational dissatisfaction among staff. The Sanctuary Model is an example of a trauma-informed approach that has been successfully applied in various human service organizations (Bloom & Sreedhar, 2008). This model is informed by trauma theory (Herman, 1997), constructivist self-development theory (McCann & Pearlman, 1990; Pearlman & Saakvitne, 1995), systems theory (Bertalanafy, 1974), and complexity theory (Waldrop & Gleick, 1992), and is potentially applicable to the dialysis unit setting.

The Sanctuary Model

The Sanctuary Model is based on theories of trauma and attachment, and examines how an individual's need for safe, nurturing and a predictable social environment is essential and reflective of physical, cognitive, and emotional responses to danger (Fonagy, 2001; Schore, 2001). This model is further supported by seminal research, such as the Adverse Childhood Experiences (ACE) Study, which demonstrated the link between adverse and traumatic life experiences and deleterious health outcomes (Felitti et al; 1998). The study demonstrated the need for the implementation of trauma-informed practices in organizations that have a high percentage of clients who present with poor coping and adjustment as a result of both past and present traumatic experiences (Felitti et al., 1998). The core components of the Sanctuary Model are (Bloom, 1997):

- Theoretical values and assumptions that derive from trauma theory

- Seven core commitments that articulate the above values
- SELF framework for problem solving and shared language

The conceptual framework of the Sanctuary Model and the application of the SELF Model to the dialysis setting can be found in Figure 1.

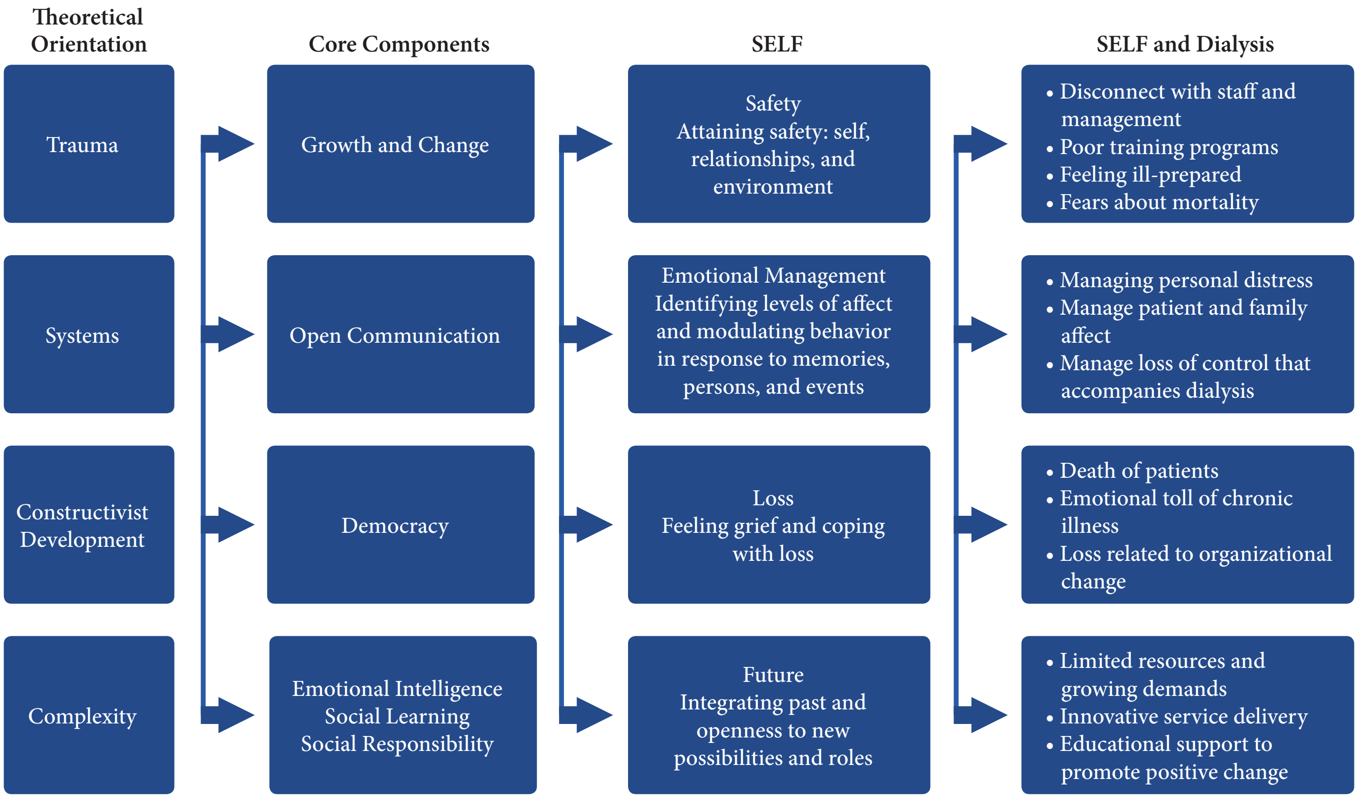
The Model for Care: SELF

A component of the Sanctuary Model, the Safety Emotion Management Loss and Future (SELF) Model is a nonlinear framework for formulating plans for client services and treatment, as well as processing organizational and interpersonal issues. The SELF Model provides a template for organizational change that is grounded in trauma-informed practice, and was originally developed for an in-patient psychiatric setting for adults who experienced trauma in early childhood (Bloom & Farragher, 2010). Trauma-informed models are frameworks to manage the impact that past and current adverse life experiences and traumas have on the day-to-day functioning of individuals, and how these injuries may have an impact on recovery for patients. Trauma-informed models aim to create systems that are emotionally safe for all members of the organization, including the well-being of the service providers. Principles of trauma-informed care include: a) understanding the impact of trauma on how people adapt and relate; b) creating and promoting safety; c) supporting choice and autonomy; and d) conducting engagement, assessment, and intervention in a theory-driven and sequential manner (Fallot & Harris, 2002).

The SELF Model incorporates these principles and has demonstrated success in various human service organizations serving diverse populations, but has not been implemented in a dialysis unit setting (Abramovitz & Bloom, 2003; Bloom et al., 2003; Bloom & Sreedhar, 2008; Madsen, Blitz, McCorkle, &, Panzer, 2003). The theoretical conceptualization of the SELF Model is grounded in empirical data and suggests that therapeutic milieus and social service organizations can use democratic processes to make complex decisions. These systems engage clients by focusing on the many domains of safety: psychological, spiritual moral, and social. This information is used to create responsive interventions (Bloom & Farragher, 2010; Esaki et al., 2013).

Although this model of care has been primarily utilized for social service organizations serving psychologically injured individuals, there is evidence suggesting it may be appropriate for the dialysis unit setting, including recent trauma work in pediatric oncology and medical trauma centers (Kassam-Adams et al., 2014; Kazak et al., 2006; Pynoos et al., 2008). Knowledge from these reports can aid in better understanding how trauma-informed approaches could be useful in various healthcare settings where patients often experience high symptom burden and high rates of mortality, such as in dialysis. For example, Kazak et al. (2006) found that when a medical oncology unit was given psycho-education on the impact of trauma on functioning, they could better respond to the emotional needs of the clients and the families that

Figure 1. Sanctuary's SELF Model applied to the Dialysis Unit Setting



they served. The National Child Traumatic Stress Network (NCTSN) developed a trauma-informed toolkit entitled "Medical Traumatic Stress Toolkit" for medical facilities that treat children. The aim of the Toolkit is to assist the medical team in dealing with the stress and loss associated with the medical traumas (NCTSN, 2004). Kassam-Adams et al., (2014) surveyed 200 pediatric nurses on their opinions and knowledge of trauma-informed care. The nurses reported that barriers to implementing trauma-informed care included time constraints, training, and worry about re-traumatizing patients. This study demonstrates the ongoing need for more research to better understand the implications of trauma-informed practices.

Although there is growing interest in incorporating trauma-informed models into healthcare settings, little research exists regarding the early childhood experiences of dialysis patients or the present traumatic experiences for this population. For patients who have experienced childhood traumas, the psychological pain of dialysis could result in more problematic behaviors, including medical non-compliance, and increased service utilization (Tagay, Kribben, Hohenstein, Mewes, & Senf, 2007). Tagay et al., (2007) report in a study of over 144 hemodialysis patients that almost 80% of participants reported having experienced at least 1 traumatic event. Of this 80%, only 10% of the reported traumatic events were associated with hemodialysis. Tagay et al., also found that patients with Post Traumatic Stress Disorder (PTSD) showed significant decreases in mental health, including depression, anxiety, and life satisfaction compared to patients reporting no PTSD symptoms. If individuals have healthy adaptive responses, encountering stress can produce resilience. However, if the stress or experience is unrelenting and chronic, which is often the case with long-term diseases, it can wear down the body and create difficulty regulating internal states and managing strong negative emotions, such as fear and shame (Duman, Malberg, Nakagawa, & D'Sa, 2000). Many trauma survivors manage strong affect with dissociative defenses by shutting off from emotional experiences and as a result engage in avoidant coping mechanisms that eventually trigger intrusive memories or flashbacks (Herman, 1997). Other survivors attempt to self-sooth through self-harming re-enactments of past trauma (Brown, 2006; Linehan, 1993). This re-enactment is often experienced as self-sabotaging behavior that frustrates service providers and translates into relationship difficulties (Bloom & Farrangher, 2010). For service providers who are unaware of these dynamics, these relational patterns become assessed as lack of compliance, poor motivation, or ways to intentionally or unintentionally punish the provider. This may push the provider to become cold and punitive.

Regardless of whether or not adverse patient experiences result from past or present traumatic events, such events can lead to defensive responses that could have an impact on treatment outcomes and the environment in which treatment is provided (Davison, 2007; Dermody & Bennett, 2008; Kaveh & Kimmel, 2001; Kimmel, 2000). Despite little evidence regarding trauma and the dialysis population, there is potentially significant value in developing a trauma-informed culture in the dialysis unit setting. The implementation of such a program could potentially improve patient outcomes, and reduce the overall risk of dialysis staff exhibiting symptoms of collective trauma similar to those of their patients. The following case example will help to further demonstrate the applicability of the Sanctuary Model in a dialysis unit setting.

Case Application

The setting for this proposal is a 20-seat dialysis unit situated in a small rural town in Pennsylvania. The patient population served is predominately white, lower-to-middle class, aged 65 and older, with an increasing number of patients in their 80s who reside in a nursing home setting. The unit is staffed by registered nurses (RNs), licensed practical nurses (LPNs), and technicians, all of whom provide direct care to the patients. The leadership for the unit consists of one unit RN team leader, an operations manager, and a medical director. Additional staff members include three dietitians, one chaplain, a licensed social worker, a certified registered nurse practitioner (CRNP), three nephrologists, and a secretary. The dialysis unit is open daily, with the exception of Sundays from 6:00 a.m. to 4:00 p.m. On average, 70 patients receive treatment at this unit. The renal social worker would be responsible for introducing and implementing the SELF Model. Table 1, column 3, further illustrates the issues and interventions addressed in each module of the SELF Model described below.

Identified Problems as They Relate to the SELF Model

The dialysis unit setting as it relates to the SELF Model can be described as an environment that involves problems related to safety, emotional management, loss, and future. When patients and staff do not feel safe in this environment, present with difficulty managing emotions manifested from the environment, or struggle to cope with feelings related to loss, there is potential for poor outcomes including decreased staff and patient quality of life (Chan, Brooks, Erlich, Chow, & Suranyi, 2009; Jablonski, 2004). A clear understanding of how these problems manifest among staff and patients is valuable for renal social workers to effectively facilitate interventions and empower staff and patients to create a healthy and meaningful treatment experience.

Safety. Workplace stress as it relates to safety can be particularly paralyzing in the dialysis unit because staff are continuously faced with their own mortality when working with patients who have a terminal illness. Safety in this context is defined as feeling psychologically safe, as well as safety in relationships and in the environment (Bloom & Farranger, 2010). This means people can feel free to express their emotions and, in turn, have a predictable environment where they feel cared for. In dialysis units and in hospital settings, mortality and the associated feelings are often unexpressed and repressed. Unconsciously and consciously, this can lead to staff feeling unsafe, which is likely to lead patients to feel unsafe. Therefore, it is important for staff to have space to express and work through their own emotions and express what is bothering them, to unearth disassociated emotions so that they are able engage in emotionally satisfying labor. When this happens, they will more likely create a well-regulated and emotionally attuned environment for patients and can tolerate and respond to the varying affective states that patients may express. This shifts the service from being crisis-driven into an empathic interaction that is satisfying to the staff and responsive to patients' needs. Specific concerns about safety in the case example are comprised of: a) a disconnect between staff and management that leads to decreased autonomy and low morale among staff; b) conscious fears about poor training programs and ill-prepared staff; and c) unconscious and conscious fears about personal mortality. Importantly, staff members from the case example often express feeling "silenced" by management regarding their concerns for safety.

The dialysis unit continues to experience a high turnover rate for registered nurses (RNs). RNs must be trained for six months before they can independently work with a patient and take on-call. Despite this six-month training process, some RNs have transferred to other positions, leaving the nurses who trained them feeling frustrated, overwhelmed, and betrayed. When good people leave an organization or stay unsupported and experience burnout, harm to the entire system is possible (Bride, 2007). In this case example, there is a generational gap that exists between senior nurses and newly hired nurses, resulting in a split among the staff that can be toxic for the patients. Issues regarding privacy make communication problems among the staff more complex. As with many dialysis units, this setting often does not allow for privacy among staff or patients. Furthermore, when conflict is present in the unit among staff or management, there are likely opportunities for patients to witness negative interactions among staff. When patients witness conflicts or arguments among staff in the dialysis unit setting, it is possible that safety concerns may arise or patients may develop issues of mistrust.

Although fears regarding personal mortality and illness are not openly discussed in the dialysis unit, they are unavoidable, given the nature of the work environment. Despite past high mortality rates in this unit case example, the system in place to address the death of patients or to provide support to staff when patients die is limited. Discussions surrounding loss and grief are not a priority or a part of the unit culture. Unfortunately, this approach can create an emotionally charged environment in which staff is unable to express loss, and as a result, often become detached and desensitized to patient suffering, pain, and death. This detachment has an impact on empathy and the ability of the staff to form healthy attuned relationships with the patients.

Furthermore, the employees are dependent upon systems that shape how they practice, often resulting in decreased satisfaction with work and a decreased sense of purpose. This can create vulnerabilities for the helper and negatively disrupt how they derive meaning from their reality. Work that once gave satisfaction and meaning to the worker can become burdensome. This will invariably impact the treatment and empathic engagement with patients.

Staff perceptions regarding safety can mirror the experiences of dialysis patients. Issues including dependency, mortality, and loss of control can result in feelings of powerlessness and a decreased sense of self among staff and patients. Social workers can collaborate with management to address issues of safety to help improve the culture of the dialysis unit. Examples of how safety can be addressed in the SELF Model are found in Table 1. One of the most important steps that social workers can take when introducing the SELF Model is to provide reassurance that training and workshops will be founded upon a collaborative approach that emphasizes safety. Additionally, social workers can work with management to reinforce the value of providing staff with the resources and training to promote an overall sense of respect and value among staff, management, and patients.

Emotional management. Emotional management in the dialysis unit setting has various implications for staff and patient well-being. When staff and patients do not effectively manage emotions, the outcomes can be both physically and emotionally damaging (Bremmer, 2003; Grandey, 2000). Dialysis staff who are emotionally attuned are more likely to be aware of the impact dialysis can have on individuals and their families, and as a result, should be better prepared to respond to a wide range of distressing emotions (Schore, 2003). This preparation can result in improved communication among staff, patients, and management. On the other hand, the following consequences can occur as a result of poor emotional management: a) staff burnout; b) reduced staff and patient satisfaction; c) compromised patient care; and d) a decrease in patient and staff quality of life (McQueen, 2004; Miller et al., 1995; St. Pierre et al., 2011).

Various physical and psychosocial factors may have an impact on how well dialysis patients manage their illness, including chronic pain and depression (Davison, Chambers, & Ferro, 2010). Although studies suggest that chronic pain in dialysis patients has an impact on both physical and mental health, pain and discomfort with dialysis treatment is often under-reported, poorly understood, and complex due to the multiple medications and comorbidities of dialysis patients (Davison et al., 2010; Davison, Koncicki, & Brennan, 2014). Dialysis treatment alone can result in significant changes for patients, including increased use of the healthcare system, changes in employment and level of independence, and potential challenges with intimate relationships with family and friends (Davison et al., 2010). Despite patients on dialysis having impaired health-related quality of life (HRQoL), renal providers are often unaware of patient symptoms and effective ways to reduce and treat symptoms in this population (Weisbord et al., 2007). This lack of understanding of the needs of this group may be associated with the degree to which emotional symptoms affect patients' HRQoL (Weisbord et al., 2007). Furthermore, patients' emotional responses to dialysis or past traumas that are triggered by dialysis can make treatment more challenging for staff, particularly when they cannot adequately manage their own emotions relative to their patients (Kazak et al., 2006). When the dialysis staff is unable to manage their own emotions, they can create an environment filled with "emotional contagion," placing patients in an unhealthy and potentially controlling environment, of which they may try to avoid (Bloom, 1997, p. 42.). Organizing and making meaning from a distressing experience is critical to the recovery process of patients living with chronic illness (Seifter, 2010). This may mean that a healthy treatment environment would involve best practices for managing both patients and staff emotions as they relate to exposure to chronic illness.

Support programs that help staff and patients identify, understand, and manage their emotions could be very beneficial in dialysis units. Social workers can work with staff and management to develop training and workshops that aid staff in better understanding the role of staff and patient emotions in the dialysis unit setting. Specifically, workshops that focus on emotions related to fear, death and dying, loss and grief, and dependency will provide a good foundation for staff to understand how to manage personal and patient distress (See Table 1.).

Loss. Loss, as it relates to dialysis patients and staff, can result in poor coping and decreased quality of life (Chan et al., 2009; Jablonski, 2004). In this dialysis unit case example, specific concerns about how loss is felt and handled include: a) loss as it relates to physical and emotional aspects of chronic illness; and b) loss as it relates to organizational change. Dialysis staff can witness profound loss with their patients, including amputations, loss of finances, loss of independence, loss of employment, and loss of life (Chan et al., 2009; Jablonski, 2004; Kimmel & Peterson, 2005). Although more information is needed to better understand aspects of loss with this population, current research suggests that loss caused by chronic illness can result in a grief response that can profoundly impact coping and lead to depression (Chan et al., 2009; Israel, 1986).

Dependency on dialysis alone can create tremendous feelings surrounding loss of control. This experience may trigger memories of resolved and unresolved trauma that manifest in poor coping skills that staff need to help patients navigate. Given this aspect of treatment, it is important for patients to not be subjected to an environment that reinforces this loss.

Dialysis unit personnel can become "emotionally anesthetized" as a result of experiencing traumatic losses of patients on a frequent basis (Bloom & Farragher, 2010, p. 181). This level of emotional desensitization could be particularly damaging and result in decreased support from staff. Although limited data exists regarding the degree to which staff social support improves outcomes in dialysis patients, studies have demonstrated a link between social support from healthcare staff and patient quality of life (Patel, Peterson, & Kimmel, 2005; Untas et al., 2010). Dialysis staffs' level of exposure to loss is unique, and if not properly managed could result in emotional exhaustion, decreased job satisfaction, and disengagement from the staff-patient relationship (Maslach, 2003; O'Brien, 2010). It is critical to acknowledge and name losses, even when one is an expected part of prognosis. It acknowledges the dignity of the person and recognizes that losses can have a differentiated impact depending on context.

Dialysis unit staff may also experience loss when they are exposed to continuous changes, or an environment that is not perceived to be supportive or empowering (Hochwalder, 2007; Lachinger & Leiter, 2006; O'Brien, 2010). The difficulty that staff has accepting the changing climate of the healthcare industry may mirror the difficulty that many patients experience when faced with changes related to their illness.

It is not uncommon for dialysis patients to exercise their will in a self-deprecating manner when they are confronted with loss (Chan et al., 2009; Witenberg et al., 1983). Many patients may experience a false sense of satisfaction and control even when they make poor decisions about their health; for example, they may eat the wrong things, drink too much liquid, or make a conscious choice to not take medication (Chan et al., 2009).

Similarly, dialysis staff may react to environmental changes and constraints with resistance or resentment. This coping response can develop when loss of autonomy is experienced with regards to decision-making within the unit. However, when staff perceive they have control over the environment and believe that their values align with that of the organization, they are more likely to experience psychological empowerment (O'Brien, 2010; Rappaport, 1987; Spreitzer, 1995). Resistance to change by both staff and patients often results from a fear of losing the past and giving up what is comfortable, even when it is unhealthy (Bloom & Farragher, 2010). For staff and patients alike, accepting change can be one of the most difficult challenges to overcome.

Support programs, focused on fear and conflict as essential parts of the growth process, can help individuals approach loss in a healthy and productive manner. Social workers can collaborate with staff and management to create a dialysis unit culture that embodies psychological empowerment. This focus helps clients and staff recognize the importance of self-determination and interdependence. Self-determination and interdependence are core components of social work training and practice, and play key roles in positively changing the dialysis unit setting (Council on Social Work Education, 2008; Gutierrez, Glenmaye, & DeLois, 1992, Gutierrez, Glenmaye, & DeLois, 1995;). Suggestions for how to begin to facilitate workshops focused on loss are found in Table 1.

Future. The future as it relates to the dialysis unit setting is filled with fear, excitement, and hope. Staff and management need to embrace change within the healthcare delivery system. In addition to a highly demanding and growing dialysis population, there will be even larger systemic changes within the healthcare industry and society that will significantly affect how care is provided and received (USRDS, 2014). Limited resources, greater demand, and higher expectations of service will make for significant potential challenges (Hawkins, Shohet, Ryde, & Wilmont, 2012). Characteristics of helping professionals, such as those who engage in dialysis work, include feelings of satisfaction from helping others cope and heal (O'Brien, 2010; Sabo, 2011). However, when organizational optimism is not nurtured, and professional development is not encouraged or supported, helping professionals' satisfaction levels can decline (Kouzes & Posner, 2012; O'Brien, 2010). It is important to nurture organizational optimism by conquering present issues with an eye on future challenges and changes in order attain long-term sustainable goals in health service organizations. The future success of the dialysis unit presented will depend greatly upon awareness, healing, and professional growth among staff and leadership, and will be measured by the level of staff satisfaction and patient outcomes.

Through education and support, social workers help institutions change (Cummins, Byers, & Pedrick, 2011; Netting, McMurtry, Thomas, & Kettner, 2011). Targeted efforts enable social workers to empower clients and deter the impact of hopelessness on clients' sense of self and their relationships. In the same vein, social workers can empower organizations to address past, present, and future barriers to cultivate an environment that is responsive and dynamic. Furthermore, the profession is action oriented and grounded in efforts to make changes at all levels of practice (Cummins et al., 2011; Netting et al., 2011). This approach to change is particularly important in the dialysis unit setting, where resistance to change among staff could potentially result in decreased quality of care and poor job satisfaction (Huber, 1995). Social workers can develop workshops with management and staff that focus on promoting acceptance of change and emphasizing understanding, psychological empowerment, and sustainability. Suggestions for potential workshops are listed in Table 1.

The following is a brief proposed implementation plan for the SELF Model (See Table 1.) designed for the case example. This proposal can be used as a guide for other units to consider when utilizing Bloom and Farragher's (2010) Sanctuary Model, of which SELF is a component.

IMPLEMENTATION PLAN

Phase 1

Upon receiving support from senior leadership of the organization, a module for each specific area of SELF will be developed in collaboration with the regional governing body for the dialysis unit (in this case Network 4) and the dialysis unit staff. The unit social worker will then organize and facilitate each module. The first stage in this phase will involve a community meeting among staff and management to cultivate safety and trust. During this process, expectations and goals will be clearly defined to help create a predictable and safe environment. The social worker will hold an educational in-service for staff and management on trauma and stress in the dialysis unit setting, with a specific focus on the value of understanding how emotional labor affects the body and the mind, and ultimately, patient outcomes. Additionally, staff will be matched with one of the four following modules: Safety, Emotions, Loss, and Future found in Table 1.

Timeline: All four modules will be completed quarterly over the course of a year. Each specific module will run for four weeks, during which time staff assigned to the module will present a weekly in-service.

OUTCOMES AND MEASURES

For each SELF-Module, the staff will design a questionnaire to address competency, knowledge base, and overall level of staff satisfaction to determine effectiveness of the program and address future needs of patients and staff. Staff will receive questionnaires pre- and post-module. Additionally, the unit social worker will provide the staff with the Professional Quality of Life Scale (ProQOL) prior to the start of the modules and after the final module is completed (Stamm, 2010). Additional outcomes measures addressing patient quality of life, psychological empowerment, life stress, and conditions for work effectiveness will be considered.

Phase 2

Staff and patient satisfaction surveys, along with other identified appropriate measurements, will be distributed and reviewed yearly to identify areas needing improvement and support. The dialysis staff will be annually assigned new modules that will focus on all 4 areas of SELF and will be responsive to contextual changes in the unit and in practice to ensure diversity of learning in the workplace.

CONCLUSION

Bloom and Farragher's (2010) SELF Model provides a framework within which dialysis units can begin to develop unit-specific designs that foster a healthier working environment. Dialysis unit social workers are in a unique position to champion and assist implementation of such programs. The changing dialysis environment, including the increasing needs of dialysis patients coupled with a reported nursing shortage and an increase in burnout, signifies a call for greater attention to the needs of the staff (Gardner, Thomas-Hawkins, Fogg, & Latham 2007). Emotional labor that involves work overload, death and dying, uncooperative patients and family members, and high job demands can have a poor impact on nurses' stress levels (Lambert & Lambert, 2001). However, with the proper tools and guid-

Table 1. SELF-Modules and Objectives

Module	Workshop and Objectives
Safety Module	• Define what safety means to you personally • Define the different types of safety (physical, psychological, social, and moral) • Define safety as it relates to patients and devise a plan to ensure optimum physical and emotional safety of patients • Identify the importance of boundary making in the dialysis unit setting and how appropriate boundaries improve staff and patient outcomes • Identify manageable change that can result in a safer working environment for staff and patients
Emotions Module	• The basics of understanding emotions for staff and patients • The emotional impact of fear as it relates to death and dying • The role of emotional intelligence in the dialysis unit • How chaos in the dialysis unit can be emotionally paralyzing
Loss Module	• Defining loss as it relates to self • Defining loss as it relates to dialysis patients • Recognizing the value of self-determination • Understanding the role of loss in personal growth and organizational change
Future Module	• The value of understanding the past in order to move toward a healthier future • How power is perceived and utilized by staff and patients • How to prevent becoming learning-disabled organization • Preventing self-fulfilling prophecies and traumatic reenactment • Breaking away from non-adherence and embracing cultural change and sustainability • Working toward an organization that promotes psychological empowerment

ance, these complex aspects of care can be managed in a sustainable and healthy environment in which staff and patients experience high levels of satisfaction. Frontline or direct care practitioners find meaning and satisfaction in their work and have less resilience when they have adequate training, coping strategies, and supportive work environments (Bride, 2007; Craig & Sprang, 2010; O'Brien, 2010). Adequate training allows them to have a specialized understanding of their patients' needs, including emotional regulation. Improved coping strategies equip them to detect, monitor, and treat their own work-related stress and creates a supportive work environment that communicates that the organization is invested in the well-being of the staff as opposed to reactions to ongoing crises.

Trauma-informed support programs designed to help dialysis staff effectively manage the challenges of this high-stress environment are valuable, and can be facilitated by Master's-level renal social workers. Social workers are trained to be change agents at all levels of practice and understand the interconnectedness of micro- and macro-environments (Netting et al., 2011). This is especially important in the dialysis unit setting, where organizational stress can result from poor preparation to cope with overexposure to traumatic incidents. Furthermore, trauma-informed interventions aimed at improving outcomes for clients and organizations are growing in social work practice and education (Breckenridge & James, 2010).

This proposal provides the design for renal social workers to develop an on-site trauma-informed program that fits the needs of their dialysis unit setting. The authors recognize that renal social workers have extensive job responsibilities and may not have the time to devote to comprehensive staff interventions. However, there are many aspects of the SELF Model that can be applied in smaller increments over longer periods of time, making application of this model more feasible. Additionally, renal social workers can assume the roles of facilitators and leaders through introducing innovative interventions that have the potential to improve outcomes for patients and staff. Further research in this area addressing the effects of this model on staff and patient quality of life is warranted. The proposed module in this manuscript will be introduced and implemented in 2016 in a dialysis unit known to one of the authors. Measured outcomes for the proposal will include professional quality of life (including compassion satisfaction, compassion fatigue, and burnout), patient quality of life, psychological empowerment, and conditions for work effectiveness. There is compelling information that suggests that trauma-informed staff interventions in dialysis unit settings could positively impact professional quality of life and patient outcomes. Further attention to this area of practice is needed to best understand feasibility and acceptability of such interventions by renal social workers.

AUTHOR NOTE

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Improving Health Literacy in Kidney Patients: Nephrology Social Workers as Leaders

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This article will discuss two research studies related to health literacy (HL) and nephrology: one conducted with dialysis patients at facilities in New York City on health information seeking behaviors, and one conducted with nephrology social workers on their use of health literacy knowledge, tools, and assessments. The results of both studies were presented at a roundtable event hosted by The Rogosin Institute in New York City to inform a discussion around improving health literacy of renal patients, their families, and care teams. The authors define health literacy, then discuss the methods and findings from both studies, and finally, drawing from both studies, make recommendations for nephrology social workers to improve health literacy among kidney disease patients and their care partners.

INTRODUCTION

Research suggests that nearly 9 in 10 adults in America have trouble understanding some or all of the health information they receive from their healthcare providers or from publically available materials (DHHS, 2010). This lack of understanding makes informed decision making impossible, and limits patient empowerment. Health literacy (HL) is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (DHHS, 2010). Low health literacy has been associated with higher rates of disease and poorer management of conditions (Dageford & Cavanaugh, 2013; Devraj et al., 2015). Recognizing the immense problem of low health literacy nationwide, in 2010, the U.S. Department of Health and Human Services released *The National Action Plan to Improve Health Literacy*, which is based on two key principles: 1) the universal right to accurate health information, and 2) the need for healthcare to be delivered in a way that benefits the patient’s health and quality of life (DHHS, 2010).

Social workers play an essential role in ensuring patient understanding of a diagnosis, and have the potential to make a significant impact on improving HL nationwide. Social workers are in tune with the importance of communicating effectively with clients in many different ways. Nephrology social workers (NSWs) provide support and communication, ranging from a simple hug, fist-bump, or high-five, to an intense, emotional end-of-life discussion. These interactions may be one-on-one with a single patient or involve a few to many family members. NSWs act as advocates for patients, and insist that their patients’ views be heard and respected, even if that voice conflicts with the opinions of the medical team, family members, or social norms.

In March 2015, The Rogosin Institute, a not-for-profit kidney care organization based in New York City, hosted a roundtable event that brought together experts in the fields of kidney disease and HL to discuss ways to better educate kidney patients and empower them to take charge of their healthcare. Hosted by Rogosin’s Jack J. Dreyfus Center for Health Action and Policy (CHAP), the roundtable included individuals with kidney disease as well as nephrology representatives from medicine, nursing, social work, nutrition, health education, policy, and dialysis unit administration executives. Participants came to the roundtable from all over the United States to discuss the biggest challenges facing patients with chronic kidney disease (CKD) and end-stage renal disease (ESRD), and to brainstorm ways to address these challenges. The goal of the roundtable was twofold: 1) the development of actionable projects for pilot in New York City and/or other communities around the country, and 2) to publish and increase dissemination of information about HL and kidney disease. Two studies were presented at the roundtable: one related to patient experiences and barriers to learning about their kidney disease, and the other about NSWs’ use of health literacy tools.

CKD and ESRD rates are growing in the U.S., and without adequate information and understanding about how to slow or halt progression, the number of patients with progressive kidney disease will continue. Kidney disease affects over 26 million people in the U.S., and over 600 million worldwide (Dageforde & Cavanaugh, 2013). Treating individuals with kidney disease is expensive; although they represent only 1.5% of Medicare patients, the treatment of people with ESRD takes 7.5% of the Medicare budget. When the treatment of people with CKD is added, the figure rises to nearly 17% of the Medicare budget (Saran et al., 2015). More attention must be paid to health education and disease prevention. HL tools and techniques need to be incorporated into the daily routines of all healthcare organizations and providers.

HEALTH LITERACY (HL)

Today we are bombarded with messaging—including health messaging—from media, healthcare providers, and other sources. Despite the abundance of information, too many people still struggle to understand their healthcare needs, properly take medication, or follow instructions from their clinicians. Koh and Rudd suggest that we are living in a troubling paradox where “people are awash in knowledge that they may be unable to use" (2015). Simply having information available is not enough; it must be easy to understand and use. While health literacy and general literacy are certainly related, health literacy requires understanding of complex health systems and a medical vocabulary, which can be difficult for even well-educated people, particularly given the rapid changes in healthcare. Social and cultural factors influence health literacy, as well; individual beliefs, value systems, and traditions have an impact on the way people perceive and receive health information (The Joint Commission, 2007).

Limited HL is associated with poor health outcomes, including increased emergency room visits and hospitalizations, lower patient satisfaction, poor adherence to treatment plans, and death (Dageforde & Cavanaugh, 2013; Devraj et al., 2015; Liechty, 2011). Miscommunication or misunderstanding in healthcare can create an unsafe environment for patients (The Joint Commission, 2007). In the U.S., an estimated 90 million people have basic or below-basic HL skills. Only approximately 12% of U.S. adults have proficient HL (Dageforde & Cavanaugh, 2013; Koh & Rudd, 2015). Low HL disproportionately affects people who are older, have lower educational attainment, and come from lower socioeconomic status communities. These risk factors for low HL are among the same risk factors for kidney disease. Therefore, people at risk of developing kidney disease often have greater challenges in understanding, managing, and being engaged in their healthcare (Dageforde & Cavanaugh, 2013).

STUDY 1: PATIENT EXPERIENCE

The first study was presented at the roundtable event to ensure that patients' voices would be included in the discussion. Members of the Rogosin team conducted interviews with 41 patients at six dialysis units around New York City. The interviews, approved by the Weill Cornell Medical College Institutional Review Board, were conducted as part of a patient engagement study to reduce disparities in kidney disease. Participation was completely voluntary. Staff members at CHAP conducted the interviews during patients' dialysis treatment. Some interview participants were selected at random, while others were approached based on recommendations from unit social workers and administrators. Interview questions gathered respondent demographics, information-seeking behaviors, and the level of understanding about their health conditions. Respondents were varied in gender (54% female, 46% male), age (range from 24 to 88; average age 66), race (37.5% White, 40% Black, 12.5% Hispanic/Latino, 7.55% Asian), and language spoken at home. The majority of respondents spoke English at home (85%); however, others spoke Spanish, French, Chinese, or Arabic. Language was a limiting factor in this study, because the researchers did not have translation services available while conducting the interviews. One of the researchers was fluent in Spanish and conducted one interview in Spanish; however, the remaining interviews were conducted in English. Respondents had been on dialysis for as short as two months and as long as 15 years.

Interviews were recorded, and results were entered into the REDCap (Research Electronic Data Capture) system, coded, and analyzed for common themes. Respondents were asked if they wanted to learn more about their kidney health and disease, and how they liked to learn. More than half of respondents (58%) wished they knew more. The majority of respondents (65%) shared that they received most information about their kidney health from their doctor, nurse, social worker, dietitian, or dialysis technician. Others received information from pamphlets, the Internet, books, or other patients. Respondents were also asked if they felt that videos about kidney health, brochures, group classes, or more time with a doctor or nurse would be helpful. The vast majority (84%) expressed a wish for more videos to help them learn about their kidney health. Nearly two-thirds (64%) felt that more brochures and written materials would be helpful, and over half of respondents (55%) were interested in group classes to learn more. When asked if more time with their doctor or nurse would be helpful, only one-third (36%) of respondents felt this would be helpful, stating they had ample time to ask questions of their healthcare team during their dialysis treatments. Additionally, respondents were asked a series of questions about their difficulty understanding medical materials, including patient education materials, medical forms, and care plans. As seen in Table 1, responses were varied; some patients had no trouble with medical materials while others found it extremely challenging and needed additional assistance to understand and follow medical materials and recommended care plans.

Respondents were also asked about their comfort level with technology and their interest in using technology-based educational materials, including tablets to view videos and interactive programs. Approximately half (51%) of respondents had used the Internet to research their health condition, and 53% owned a smartphone or tablet. When asked if they would use tablets to view educational materials during their treatment if they were provided by the unit, nearly three-quarters (71%) said they would, and the vast majority (88%) said they would watch educational videos during treatment or at home if they were available on the Internet.

Responses to questions about what sort of information and support these patients felt were missing from their healthcare experience were varied. Many respondents shared that they wished they had more information at the time of diagnosis, possibly in the form of structured courses leading up to the start of dialysis. Some wished they had a better understanding of how the dialysis machines worked. Others wanted for more information was available about access and reasons for fistulas versus catheters. Many respondents wanted more information about the transplant process. Patients expressed a desire for educational materials in more languages to improve the understanding of non-native English speakers.

In addition to information, many respondents wanted more emotional support—for themselves, their families, and their care partners. They wished there were more ways to engage their families and care partners in their healthcare. This reflects the importance of the NSW's role in providing emotional support for adjustment to chronic illness, an important step toward patient engagement and empowerment for self-management of care.

Analysis of the interview responses revealed a number of key themes related to improving HL, including:

- The importance of tailoring patient information to the individual's experience and cultural background.
- The importance of addressing mental health challenges that patients face.
- Everyone needs more support as they cope with and navigate their diagnosis; even individuals with the best personal support systems need more support.
- Honest communication between providers and patients is essential.
- Patients can—and should—play a significant role as advocates in their communities to educate their peers about kidney disease prevention and to improve health outcomes for people at risk for kidney disease or those who have been diagnosed. When patients take a lead role in outreach and education, information can be delivered in a way that is relatable and accessible for diverse communities.

STUDY 2: NEPHROLOGY SOCIAL WORKER SURVEY

To learn more about the current status of HL in settings that serve kidney patients, an informal survey was developed, approved by the Council of Nephrology Social Workers' (CNSW) Executive Council, and then distributed to CNSW members in January 2015. The 10-item questionnaire was sent via the CNSW general listserv. Over the course of three weeks, 66 responses were received, representing approximately 10% of the CNSW membership. Eighty-six percent of those respondents were working in a dialysis setting and 14% in transplant.

This is a summary of the responses by CNSW members. No statistical analysis was conducted. Results can be seen in Table 2.

Based on the survey responses, NSWs view HL efforts as an important component in patient education and self-care management. However, few clinics currently measure the HL skills of patients. For a clinic to implement the use of HL techniques effectively with all staff, respondents believed there was a need for systematic implementation of HL education and skills training in the clinical setting. NSWs report being comfortable in the role of assessing HL, which is done by asking open-ended questions, usually during the psychosocial evaluation assessment. Common questions include:

- Can you tell me what your doctor has told you about your kidney problems?
- What do you know about why you need dialysis?
- What medications do you take, and what are they for?

More concrete questions that have an impact on HL concerns include:

- Who, if anyone, comes to doctor's appointments with you to listen and ask questions?
- Do you prefer to complete medical forms on your own, or do you want assistance?
- Do you have vision or hearing concerns?
- Which language do you prefer to use when speaking or reading about your healthcare needs?

Table 1. Patient Understanding

Question	Answer	Percentage
How often do you have someone (family member, friend, hospital/clinic staff, caregiver) help you read medical materials?	Always Often or sometimes Never	23 15 62
How often do you have problems learning about your medical conditions because of difficulty understanding written information?	Always Often or sometimes Never	3 31 66
How often are medical forms difficult to understand and fill out?	Always Often or sometimes Never	17 43 40
How often do you have difficulty understanding and following your annual care plan/planning information you receive?	Always Often or sometimes Never	29 27 44

Although NSWs feel fairly comfortable with HL, they mainly use open-ended questions, and only half use teach back techniques routinely; very few are aware of the validated tools to assess HL. This survey suggests that they would like more training to develop formal HL skills.

MOVING FORWARD

Based on the results of both studies, it is clear that patients want more information in a clear and informative manner, plus more support. NSWs are interested in more training to develop HL skills. Practical tools and techniques that NSWs and other healthcare providers can use include:

- *Using "universal precautions" for HL*: Providers have traditionally assumed that patients understood the information they presented unless questions were raised to suggest otherwise. Universal precautions take the opposite approach and assume that patients may have difficulty understanding healthcare information. The concept promotes the use of simple language, patient support services, and the creation of an easily navigated health system or office environment (AHRQ, 2015).
- *Using teach-back:* Asking patients to summarize what the clinician told them in their own words. This allows a provider to determine whether or not they were successful in providing the information clearly. Practitioners, including NSWs, can say to a patient "Help me see if I left anything out by telling me in your own words what you understood," which places the burden of communication and understanding on the provider instead of the patient (AHRQ, 2015).
- *Asking patients, "What questions do you have?"* instead of "Do you have any questions?" This technique encourages asking questions.
- *Using simple drawings and models* to help explain complex medical concepts.
- *Limiting information shared* to two or three points at a time, to prevent overwhelming a patient or their family.

With more training in the use of these validated tools and techniques to improve HL, both NSWs and patients can benefit, improve health outcomes, and increase active participation in care. NSWs can help patients navigate the healthcare system and direct them to high-quality information that is available and accessible.

The Institute of Medicine released a report in June 2012 listing 10 attributes of a health-literate organization, or organizations that actively work to improve patient experience and ease of navigation of healthcare systems and services. These attributes include:

1. Leadership that is actively engaged in HL;
2. Integration of HL into all aspects of organizational planning, evaluation, and quality improvement initiatives;
3. A well-prepared and trained workforce;
4. Inclusion of patients or population served in the design and development of materials and services;
5. Meeting the needs of population served while avoiding stigmatization;
6. Consistent use of HL tools and strategies in all levels of communication;
7. Readily available health navigation services and information;
8. Distribution of different forms of easily understood health information;
9. A focus on addressing the needs of high-risk patients and situations; and
10. Open communication about fees and health insurance coverage. (Brach et al., 2012).

Improving HL skills can help kidney care facilities improve health outcomes. To implement the needed systematic changes, support must come from the top down.

Social workers are trained to listen more than talk, to observe verbal and non-verbal cues, to interact in a culturally sensitive manner, and to rephrase questions. Medical social workers tend to do their most important work after the other healthcare team members leave the room; the often panic-stricken patient and family members turn to the social worker with fear in their eyes and questions. NSWs can clearly and calmly explain the complex medical terms and treatment options, plus encourage a shocked patient to consider what works best within the patient's lifestyle, wishes, resources, and support system. NSWs know to "begin where the patient is," and slowly and surely work toward the goals set by the patient and provider. This is done while encouraging any necessary behavioral change, suggesting referrals to resources, and helping the patient help themself.

These surveys indicate the interest in and need for validated health-literate communication for both patients and NSWs. Based on their relationships with patients and families, NSWs have an opportunity to play a leadership role in advancing HL and moving their organization towards health-literate status. Our survey found that NSWs are interested in improving HL within their clinics, enabling patients to truly understand their medical status become empowered to take control of their health. Informed patients are more likely to actively participate in self-care, leading to improved health outcomes. NSWs, together with patients, can implement systems, programs, and support that will increase HL among the communities served that will ultimately improve health outcomes and quality of life.

Table 2. NSW Survey Results

Question:	Answer	Percentage
Health Literacy is assessed at my clinic.	No Yes	70 30
If HL is assessed, which staff member does it?	Facility MSW Facility RN Nephrologist Dietitian CKD Educator Primary Care Provider CKD (pre-dialysis) MSW	36 20 17 15 5 4 3
Is HL assessed during the psychosocial evaluation?	Yes, all of the time None of the time Only when indicated (i.e., if low education level or non-English speaking) Most of the time Sometimes Rarely	32 26 20 12 7 3
A patient's education level is a good indication of HL.	No, but is commonly used No Yes	58 27 15
I am comfortable with my skills to provide good communication in a HL manner.	Yes Would like more guidance No response	73 24 3
I use techniques such as "teach back" or asking patients to repeat instructions in their own words to ensure that patients and families understand.	Most of the time Sometimes Rarely Never	44 39 11 6
HL is an important issue that: (Respondent could check multiple responses.)	Needs to be addressed Will require a systematic, interdisciplinary change within my clinic Not a focus at my clinic Needs to be addressed, but not a priority for me	70 47 27 9
What tool is used to assess HL?	Open-ended questions (no validated tool) Single Item Literacy Screener Short Assessment of HL (SAHL) Rapid Estimate of Adult Literacy in Medicine	96 2 1 1

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