# The Journal of Nephrology Social Work

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# THE JOURNAL OF NEPHROLOGY SOCIAL WORK

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

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# JOIN THE *JNSW* EDITORIAL BOARD

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

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

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

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

**A submitted manuscript should be accompanied by a letter that contains the following language and is signed by each author: “In compliance with Copyright Revision Act of 1976, effective January 1, 1978, the undersigned author(s) transfers all copyright ownership of the manuscript entitled ______ to** *The Journal of Nephrology Social Work* **in the event this material is published.”**

To qualify as an original manuscript, the article or a version of the article must not have been published elsewhere. Author(s) must inform the editor if the manuscript is being reviewed for publication by any other journals. Once accepted for publication by the editor, the author(s) cannot make revisions on the manuscript.

## TYPES OF ARTICLES BEING SOUGHT

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

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

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

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

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

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

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

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

## MANUSCRIPT SUBMISSION

***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.

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

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

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

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***Note:*** All tables, figures, and graphs must be produced in black and white or grayscale. Tables, figures and graphs produced in color will be returned to the auhor.

### Reference Examples

#### *Journal Article, Two Authors*

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

#### *Journal Article, Three to Six Authors*

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

#### *Journal Article, More Than Six Authors*

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

#### *Journal Article in Press*

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

#### *Complete Book, Edited*

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

#### *Chapter of an Edited Book*

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

#### *Article from a Journal Supplement*

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

#### *Abstract*

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

#### *Editorial*

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

## REVIEW PROCESS

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

## AFTER ACCEPTANCE

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

# Assessing the Effect of a Technology-Based Peer-Mentoring Intervention on Renal Teams' Perceived Knowledge and Comfort Level Working With Young Adults on Dialysis

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*The study presented in this article was part of a larger project to develop and evaluate a technology-based peer-mentoring program for empowering young adults (YAs) on dialysis and their renal teams. In this article, we focus on how the program has influenced the renal team members' perceived knowledge of, and comfort levels with, working with YAs, and their perceptions of YA behavior. We conducted surveys with 110 renal team staff members (not including the renal social workers who served as study coordinators) from 16 dialysis units in a midwestern state. The overall intervention included: (1) staff viewing a DVD of other staff discussing how to work with YAs; (2) YAs viewing a DVD of peer mentors discussing life with CKD; and (3) an opportunity for YAs to virtually "meet" with peers via a website we developed called* ***ktalk.org****. We found that the staff intervention led to improved staff perceptions of knowledge, YAs' behavioral adherence and comfort talking with the team. However, our results also revealed that staff experienced decreased comfort levels working with the young patients on dialysis.*

## INTRODUCTION

Young adults (YAs) between ages 20 and 30 account for only 2.7% of patients on all forms of dialysis in the United States, as the average age of dialysis onset is 65 (U.S. Renal Data System, 2009). While small in number, provision of care to YAs on dialysis presents significant challenges to renal teams.

How is the experience of chronic kidney disease (CKD) different for a 20 year old, as opposed to that of a 65-year-old retiree? As compared with older adults, YAs with CKD experience unique psychosocial hardships because their life course is less defined, and their adult identities have not yet emerged. The demands of kidney disease and its treatment not only pull young adults away from their usual social lives, but they also derail them from their developmental trajectories of individuation, maturation and independence (Ferris, Gipson, Kimmel, & Eggers, 2006). With an undermined self-concept and self-image, YAs with CKD often develop psychological defenses that may manifest as anger, depression and withdrawal, as well as uncommunicative and unapproachable interactions with their renal teams (Bell, 2007). Furthermore, their perceptions of the disease and the consequences of treatment non-adherence are not based on potential health risks; rather, they relate to the ways in which treatment interferes with school, recreation and daily routines, and the ways in which their peers react to their illness (Harwood & Johnson, 1999). As a result, YAs with CKD are less likely to adhere to treatment, thus increasing their morbidity and mortality risks (Saran et al., 2003; Smith & Shuchman, 2005). The long-term kidney transplant outcomes of YAs, for example, are considerably poorer than those in older age groups (Rianthavorn & Ettenger, 2005). A recent report issued to Congress describes that while young adults with CKD have the most successful 1-year kidney transplant survival rates, they also have the worst 5-year graft survival rates largely due to non-adherence to kidney transplant medications. This report also describes the significant financial impact on society and advocates for innovative interventions (U.S. Government Accountability Office, 2007). Unfortunately, there is a paucity of nephrology research regarding potential intervention strategies to help patients in this age group (Jennette & Ferris, 2006). In a few studies focused on pediatric and adolescent patients, researchers have shown that psychosocial services, as compared to traditional psychotherapy, could achieve better results (Dittman, Hesse, & Wallis, 1984; Jarzembowski et al., 2004); for example, increasing staff support time for pediatric patients after kidney transplantation leads to improved preventive care outcomes (Jarzembowski et al., 2004). Additionally, during YAs' transition from pediatric to adult programs, it is recommended that they receive open communication and be given choices by their peers, families and trusted renal team staff (Watson & Shooter, 1996). This transition clearly triggers a cultural shift from a child-centered milieu—where parents have had major input—to an adult unit where the late adolescent and YA needs to increasingly engage in autonomous decision making (Watson & Shooter, 1996).

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Peer mentoring—training selected patients to listen to, empathize with, role model for and empower other patients—has been demonstrated to be an effective approach to enhancing communication and providing patients with opportunities for informed choice (Kapron, Perry, Bowman, & Swartz, 1997; Heisler & Piette, 2005). The National Kidney Foundation of Michigan (NKFM) has experienced significant success with an adult-focused peer mentoring program; indeed, it has been shown to alleviate patients' fears about the disease and to help patients cope with dialysis and life after a kidney transplant (Wright, 2000). Additionally, in a randomized trial, this program was shown to increase CKD patients' rates of advance directive completion and to increase their comfort in discussing their wishes with their renal team (Perry et al., 2005). However, there are important challenges in extending the benefits of peer mentoring to YAs on dialysis. Because YAs constitute such a small portion of the patient population with kidney failure, many dialysis units lack access to appropriate peer mentors to advise patients in this age group.

In this research, we developed and tested a technology-enabled peer-mentoring program to support YAs on dialysis and their renal teams. This article, as part of a larger project evaluating the program's effectiveness, presents our findings on how it affected renal teams' perceived knowledge regarding the disease's impact on YAs; perceptions of YA adherence and comfort talking with the team; and staff comfort levels in working with YA patients. We were interested in studying renal team staff because, first, we suspected that much of renal teams' frustration in working with YAs on dialysis is due to the fact that they have not focused on YAs' unique challenges and care needs because they are such a small portion of their patient population. Second, we believed that if renal team members could better serve YAs, this would in turn result in improved psychosocial and health outcomes for YAs. Therefore, we created two DVDs of interviews: one with YA peer mentors and one with renal staff who have abundant experience working with dialysis patients in this age group. The YA DVD included young men and women, both African American and Caucasian, discussing how CKD and renal failure affected their lives in terms of relationships, insurance, body image, sexuality, education and careers. It also discussed their experiences in communicating with renal staff. The renal team DVD included an experienced team of nephrologists, nurses, social workers, dietitians and a physician assistant discussing the uniqueness of YAs on dialysis and effective approaches to working with them. Finally, based on extensive consultation with NKFM staff and peer mentors, we developed an online patient community website, **ktalk.org**. This website allows YAs on dialysis to anonymously interact with the YAs featured in the DVD, who acted as peer mentors on the website, as well as other YA patients who joined the community.

## METHODS

### *Study Participants*

With the assistance of the Council of Nephrology Social Workers, we first reached a sample of 46 YAs on dialysis between the ages of 18 and 32 in 18 dialysis clinics across a midwestern state. Three health care professionals (referred to as "renal team members" in this article), including nurses, dietitians, dialysis technicians and clinical coordinators, were also recruited in the study to work closely with each of the YAs. We did not include renal social workers in this study group because we relied on renal social workers in these units to serve as our study coordinators. The initial staff sample contained a total of 138 renal team members.

### *Study Design*

We conducted a prospective, pre-post trial to assess the impact of the technology-based peer-mentoring program on renal team members' perceived knowledge and comfort levels in working with YAs. Prior to introducing the intervention, we collected baseline data from the renal staff using mailed surveys. Then, the renal social workers in the study dialysis units, as part of the intervention research team, distributed the YA and renal team DVDs in all study dialysis units in March 2009. They also helped ensure that the DVDs were viewed by the intended audience within a week of receipt. Next, a registration code for **ktalk.org** was provided to all YA participants, who were told that they could talk to the YAs featured in the DVD, and others, at this website. Following this initial intervention, we allowed 2 months for YAs to register and use **ktalk.org** to interact with peers. In July 2009, we collected post-intervention data from the renal team members assessing their perceived knowledge of developmental differences between young adults and the older dialysis population, comfort working with the YAs and their perceptions of their YA patients' behavioral adherence and comfort in interacting with the renal team.

To evaluate the program's impact on renal team members' comfort in dealing with YAs on dialysis and their perceived knowledge of YA-specific treatment issues, we developed a simple renal team self-evaluation (RTSE) questionnaire. The questionnaire consisted of four items: "The patient is comfortable talking about his or her problems with me," "The patient really tries to follow the treatment plan," "Compared to other renal patients, to what degree do you feel that young adults with kidney failure are at risk for increased mobility and mortality?" and "How would you assess the renal team's level of comfort in dealing with young adults?" The first two items were assessed on a 5-point Likert scale (from 1 to 5: "strongly disagree," "mildly disagree," "neutral," mildly agree" and "strongly agree," respectively); the third question was assessed using a 4-point Likert scale (from 1 to 4: "a great deal," "somewhat," "very few differences" and "no differences"); and the fourth question was assessed using a 5-point Likert scale (from 1 to 5: "very uncomfortable," "uncomfortable," "neither comfortable nor uncomfortable," "comfortable" and "very comfortable").

The RTSE questionnaire was administered once at the baseline ($T_0$) and once at the end of the intervention period ($T_1$). The Institutional Review Board of the Michigan Department of Community Health reviewed and approved the research protocol.

*Data Analysis*

Descriptive statistics were computed for demographic characteristics as well as key study measures obtained through the RTSE questionnaire. We examined whether the renal team members' responses to the RTSE changed before and after the intervention. Accordingly, we performed paired t-tests to compare the value of these measures at $T_0$ and $T_1$, respectively.

## RESULTS

Twenty-eight renal staff left the study prior to completion for various reasons. Several were excluded from the data analysis because they changed jobs or the YAs to which they provided care left the dialysis clinic during the study period. Further, 2 social work study coordinators withdrew from the study due to lack of time, resulting in a loss of 7 YAs and 21 renal team members associated with them. The final renal team study sample therefore included a total of 110 renal team members from 16 dialysis units. The breakdown of the staff sample based on their clinical roles is depicted in Figure 1. The majority of the staff participants were patient care technicians (35%), registered nurses (34%) and dietitians (25%). On average, the renal staff participants had approximately 10 years of experience working with dialysis patients (median = 7 years).

**Figure 1.** Demographics of Staff Participants ($N = 110$)

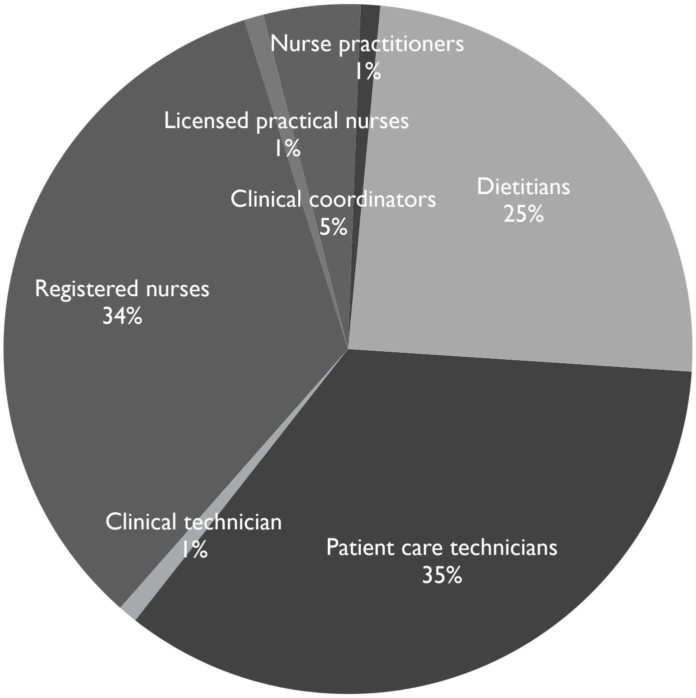

Table 1 reports the survey results obtained using the RTSE questionnaire. Before the intervention, the score for renal team assessment of YA adherence was 3.16, indicating a value between "neutral" and "mildly agree" that "The patient really tries to follow the treatment plan." At the post-intervention follow-up ($T_1$), this score was slightly higher, indicating movement in the direction of greater, though still mild, agreement. The results were marginally significant ($p = 0.09$).

**Table 1**. *Statistical Analysis Results*

| Variable | Pre | Post | *p*-value |
|---|---|---|---|
| 1. Perceived young adult adherence ("The patient really tries to follow the treatment plan.") | 3.16 ± 1.08 | 3.35 ± 1.00 | 0.09 |
| 2. Perceived young adult comfort ("The patient is comfortable talking about his or her problems with me.") | 3.71 ± 0.87 | 3.94 ± 0.79 | 0.05 |
| 3. Perceived staff knowledge ("Compared to other renal patients, to what degree do you feel that young adults with kidney failure are at risk for increased mobility and mortality?") | 3.38 ± 0.45 | 3.57 ± 0.35 | 0.01 |
| 4. Perceived staff comfort ("How would you assess the renal team's level of comfort in dealing with young adults?") | 4.26 ± 0.40 | 3.67 ± 0.89 | <0.01 |

Items 1, 2 and 4 were assessed on a 5-point Likert scale; item 3 was assessed on a 4-point Likert scale. Higher scores indicate higher levels of agreement or self-assessments.

Similarly, before the intervention, the score for the renal team's assessment of YAs' comfort talking with the staff was 3.71, again representing a value between "neutral" and "mildly agree." At the follow-up, this score was improved and the change was statistically significant ($p = 0.05$).

Further, in the RTSE questionnaire, the renal team was asked: "Compared to other renal patients, to what degree do you feel that YAs on dialysis are at risk for increased morbidity and mortality?" The mean response at T0 was 3.38, indicating an average perception between "somewhat" and "a great deal." At the post-test, this score had increased to 3.57, indicating that renal team perception of risk to YAs had increased. This change was statistically significant ($p = 0.01$). Finally, the renal team was asked about their comfort level working with YAs on dialysis. The mean score before the intervention was 4.26, indicating a response between "very comfortable" and "comfortable." At the end of the intervention period, this level of comfort had fallen to 3.67, indicating a response between "neither comfortable nor uncomfortable" and "comfortable." This change was statistically significant ($p < 0.01$).

## DISCUSSION

This pilot study points to the need for further investigation regarding appropriate supportive interventions for young dialysis patients, a small but highly vulnerable population. Because of poor dialysis outcomes and the high kidney transplant rejection rates linked to YAs' treatment nonadherence, it behooves renal care providers to provide support programs specifically designed for YAs on dialysis. Indeed, such programs may help YAs on dialysis develop better self-management behaviors while on dialysis and help assure kidney transplantation success. Clearly, traditional psychosocial services and intervention strategies designed for older adults may not be as effective when applied to the YA population, because of the many unique challenges that young patients confront. Moreover, health care providers who are unfamiliar with YAs' unique needs may be stymied in their efforts to provide appropriate support.

The results of this pilot study demonstrate the potential use of media and communication technologies to help renal team members better support YA patients with renal failure. The intervention led to improvements in several measures, including the staff's perceived knowledge about YAs' experience and the staff's perception of YA behavioral adherence and comfort level talking with the team.

The intervention may have helped improve the YAs' behavioral adherence as perceived by the renal team members. However, this change might not signify actual YA adherence improvement but a change in how staff work with YAs on dialysis based on their increased perceived knowledge of working with YAs. We suspect that as renal team members become more attuned to the unique needs of YAs on dialysis, their expectations with respect to YA behavioral adherence might readjust. In addition, there may be an interaction between YAs' motivation to adhere to treatment, alterations in staff members' approaches to care with YAs and a deepening of rapport between YAs and renal team staff.

The finding that staff members' comfort in working with YAs on dialysis decreased after the intervention was unexpected. It may suggest that, as renal team members learned more about the particular struggles of these YAs, they realized that they couldn't treat YAs exactly like other patients. This, in turn, could take them out of their "comfort zone" by upsetting previous assumptions. The decrease in staff comfort, therefore, may not necessarily represent a negative, adverse consequence of the program itself.

There are many limitations in this pilot study. First, constrained by the small sample size, we were not able to utilize the traditional randomized control trial methodology, nor could we control for variables such as staff members' years of experience or patient characteristics. The latter issue may be relevant because YAs who began dialysis as young children—who experienced the failure of several kidney transplants and never grew beyond 5 feet tall or finished high school—may face different issues than those who developed CKD and renal failure in relatively late adolescence and adulthood. Second, the program's impact was evaluated only through the staff's subjective assessments, some of which may deviate from outcomes that could be objectively measured (e.g., measures of YAs' behavioral adherence). Nonetheless, we deem staff's self-reported perception to be a critical measure of the program's success, as the quality of the relationship and communication between YAs on dialysis and their renal teams is likely driven by such self-perceived knowledge and comfort. Third, our study findings may not apply to other CKD patient populations that should receive equal attention, such as pediatric patients.

Another inherent study weakness is the notion that great change could occur for YAs within a short period of time. Clearly, providing DVDs and the opportunity for YAs to meet with peers online are not all that it takes to create a "new normal" peer group with whom to identify and develop future dreams. The authors were encouraged, however, that at the time this article was written (4 months after the trial), the YA participants were still communicating on **ktalk.org**.

## CONCLUSION

In this article, we report a study assessing the effect of a technology-based peer-mentoring program on renal team members' perceptions of knowledge and comfort working with young patients on dialysis between ages 18 and 30, as well as their perceptions of YA patient adherence and comfort interacting with the team. Despite its pilot nature, the findings reveal that this intervention shows great promise for improving these elements of renal team–YA patient relationships. We will continue to offer the website, **ktalk.org**, to the YAs participants of the study as well as other YAs with CKD, as a platform for them to connect with peers to share information and exchange emotional and social support. We will also study the YAs' activities on the **ktalk.org** website to shed light on the experiences of this group so that renal teams can proactively address their unique needs, rather than simply react to the challenges brought forward by these young patients.

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# Central Line Dissent and Fatal Dialysis Fear: The Story of Florence

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*This case study focuses on an incapable patient requiring life-saving medical intervention to which she does not assent and the ethical challenges that stem from this refusal. This article discusses the law's limitations in managing such situations as well as the difficulties for substitute decision makers (SDMs) and the clinical team when SDMs consent to treatment that cannot proceed without patient cooperation. The moral distress that befalls the clinical team and caregivers in these unique situations lead one to conclude that resources should be made available to support families who are suffering when loved ones deny needed therapies. From an ethics point of view, one can conclude that organizational support should be available to clinical teams to effectively manage these challenging cases.*

## INTRODUCTION

I watched her walk into the clinic with her mother. She looked undisturbed, almost complacent, which contrasted heavily with the butterflies in my stomach. Given the fact that she was my patient and I was her social worker, I wondered why she made me feel so nervous. Then it hit me: It was the fact that I owe her a duty, the duty of care that scares me. Of all these years in practice, I have never met someone so adamant in refusing care.

Florence is middle-aged, well groomed, neat in appearance and lives with her mother. On a superficial level, she is articulate and actively able to engage in conversations. However, after a vaguely described cognitive insult 30 years ago, she has remained cognitively limited. Both Florence and her family were unable to give a good history of what happened to cause her to be limited. According to her mother, Florence left for a vacation away from home and came back "different." It was initially reported to us was that she suffered a head injury, but the cause and further medical history following the injury is unknown. All health care team members were concerned about possible psychiatric illness. Consequently, a psychiatric assessment was requested and completed. The assessment found that her judgement, insight and reality testing were nonexistent. She was further found to be incapable of consenting to treatment and required a substitute decision maker (SDM). Underlying her psychiatric problems was a schizophrenic disorder for which she agreed to take antipsychotic medications. As with the rest of the team, she refused dialysis when the idea was brought forward by a psychiatrist.

Physically, Florence has chronic renal failure and is urgently in need of dialysis. Prognosis without dialysis is less than 6 months. She refused the central line procedure, emphasizing that she does not want dialysis. "Pricking my neck with a sharp object will damage me," she said, referring to the insertion of a neck line. The procedure and its implications have been explained to her repeatedly, as well as her impending death if she does not quickly accept dialysis. Even with the risk of death, she refuses dialysis. For the team, her refusal to accept dialysis seems irrational as the its benefits outweigh the risks, notably the risk of death.

## LEGAL PRINCIPLES AND PROCESSES

Health care legislation across jurisdictions is precise about the process of obtaining consent for treatment. There are several key principles to which one must legally and ethically adhere when seeking consent for treatment. The first principle is that the clinician proposing treatment must start the process from the presumption of capacity (Health Care Consent Act [HCCA], 1996, section 4.2). Capacity is roughly defined as a person's ability to understand information provided in order to make a decision and appreciate the consequences of giving or refusing consent (HCCA, 1996, section 4). With this in mind, every person who has decisional capacity has the right to give or refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death. Integral to this right is that all information a reasonable person would need to make an informed decision is offered and consent to a proposed treatment must be given voluntarily, not by fraud, misrepresentation or coercion (HCCA, 1996, section 11.1).

After being informed about her condition, Florence said, "My kidneys are fine. I will likely live for another 20 years without hemodialysis. Herbal teas and laxatives are all I need." Here is a person who is given correct information and asks appropriate questions, yet fails to appreciate this information within her own context. Thus, she was deemed incapable to make this health care decision for herself. Her mother was determined to be the SDM. She wanted her daughter to have dialysis but recognized the need for daughter's cooperation for the procedure. Making a scissoring motion with her fingers she stated, "If we force her to have it, she will cut the line."

As a health care team, our hands are shackled. It is a tricky situation. Here is a patient who needs life-saving therapy and who has a substitute decision maker (SDM) whom everyone on the team believes is willing to act in the patient's best interest. However, the insertion of the central line and provision of dialysis requires the patient's cooperation. If she does not assent, our ethical motivation of doing good and avoiding harm cannot be achieved. Unlike a surgical procedure for which the SDM might have given consent and the team treated the person, dialysis would be impossible in an outpatient situation because her cooperation to attend is imperative to its success. In this situation, use of restraints would likely increase her resistance, not to mention being an attack on her dignity. In a case of emergency, a health care provider can intervene without consent or involve the person's SDM. Although care may be provided without a person's consent if it is determined that the person needs care and is incapable of giving or refusing consent, the incapable individual's assent is often required to undertake invasive procedures. In this case, dialysis requires invasive preparative and maintenance procedures to which the patient does not agree. Even with the best intentions, this lack of consent places the patient, her family and the health care team in a challenging moral dilemma: Knowing an effective treatment exists but being unable to provide it.

If a person is a risk to themselves or others, he or she can be admitted involuntarily to a hospital for psychiatric assessment. With her lab values reflective of being very seriously ill and therefore a harm to herself, Florence was admitted to a hospital by the pre-dialysis clinic physician for psychiatric assessments to determine whether there were any treatable reasons for her not accepting a beneficial therapy. The assessment confirmed her psychiatric illness and incapacity to make treatment decisions but cannot offer any methods to break through the impenetrable barrier to gain her participation in a proven therapy that can help her precarious physical well-being. As such, she was at risk of self-harm through non-acceptance of therapy. However, the nature of dialysis, which is not a single event but a life-long therapy, negates the legal provisions that allow for treatment to proceed in an emergency.

Florence's dignity and how our therapies would affect her quality of life were on my mind. She was prescribed more than 10 daily medications. "I throw the medicines that stink," she told me. "It's like eating chalk." A restrictive diet lacking salt, proteins and fats was prescribed to her. In addition, she was instructed to restrict her fluid intake and watch her urine output. These commonly prescribed lifestyle changes, drugs and therapies have profound effects on patients' daily lives in ways the health care team often can barely imagine. Adding another layer, introducing her to dialysis, which requires Florence to come to the dialysis unit thrice weekly for extended hours and be connected to a machine, may have further pushed her away from the decision to have dialysis.

I engaged her in multiple discussions in an effort to persuade her to accept dialysis. As part of the medical team, it is expected that each member encourage the patient to follow the proposed prescribed treatments. The medical team is expected to save the patient's life, not watch the patient die. Florence has been seen by psychiatrists, dialysis nurses and bioethicists. After what many have described as "way above doing our due diligence," she still refused treatment. Treatment could not proceed without her cooperation. The team discharged her back home to be followed up in the renal clinic. "Prayers will save me," were her parting words.

This clinical encounter leaves the dialysis team emotionally paralyzed. "She is too young to be allowed to have a death that could have been prevented," her nephrologist said. For the team, the moral distress is enduring. As her social worker, I find myself wondering regularly whether I have done everything in my power to help her help herself. It is my role to advocate for my patient. The nagging feeling that I let her go without life-saving treatment haunts me.

## THE ROLE OF THE SOCIAL WORKER

My role as a social worker in the pre-dialysis phase and as part of the multi-disciplinary team is to educate patients and families about kidney disease and treatment options so the patient can make an informed decision. Very often the patient is overwhelmed with the information presented to them and feels lost in the process; therefore, one of the social worker's key roles is to advocate for the patient.

There are many definitions of advocacy. For this article, I have chosen the definition from Hepworth, Rooney, Dewberry Rooney, Strom-Gottfried and Larsen that defines advocacy as "one who pleads the cause of another" (2006, p. 431). Furthermore, advocacy is embodied in the values and ethics of the social work profession, "… social work profession has embraced … dignity and worth, self determination and giving voice to the powerless" (Hepworth et al., 2006, p. 431)." Bateman pointed out that the earliest origins of social work as a profession involved the advocate role. He described social workers as "possessing skills and resources to ensure the individuals who may not have a voice, who may not have the power or who are considered socially marginalized, that their interests are not overlooked or overridden" (Bateman, 2000, p. 33). Advocacy is seen as a fundamental component of social work that is written in the code of ethics, whereby the goal is to "empower and protect people who are vulnerable, poor and/or disempowered" (Bateman, 2000, p. 33).

Different types of advocacy exist. In a hospital setting, clinical advocacy refers to the social worker's skill needed in "response to patient deficits that have clear clinical relevance to the patient's health problem" (Dhooper, 1997, p. 196). To advocate for Florence is to ensure that her wishes are heard and considered, especially if her decision does not concur with the medical team. Literature dictates that advocacy involves strategies to assist the patient by way of educating, persuading, negotiating and bargaining. These strategies are either "alliance, neutral or adversarial" (Dhooper, 1997, p. 196). Literature points out that whatever style or strategy used by the advocate, one needs to remember to "ensure that the patient's autonomy and sense of mastery is not undermined" (Dhooper, 1997, p. 196). Literature is quick to point out that sometimes advocacy can produce, "a certain amount of strain and tensions: moreover a positive outcome cannot be assured" (Hepworth et al., 2006,

p. 430). Consequently, advocacy can produce conflict. The conflict is between ensuring the patient's needs are heard as well as "the needs of the institution and other health providers" (Davidson & Clarke, 1990, p. 326). Returning back to Florence's case, a conflict existed between Florence's right for self-determination and freedom of choice and her best interests as assessed by the medical team, which includes social work. This conflict created moral distress for this social worker.

Moral distress is incoherence between what one sincerely believes to be right, what one actually does and what eventually transpires (Webster & Baylis, 2000). A dilemma can arise if the advocate is expected to maintain and encourage the team's recommendation to the patient, simultaneously ensuring that the patient's wishes are taken into account. The moral distress is further complicated if the patient has been found to be incapable of making treatment decisions for his or her health care. Does the social worker's role change because Florence was found incapable? This circumstance puts further onus on the advocacy role, as the patient is not able to champion her cause.

Hemodialysis (HD) is typically performed in areas that are visible to staff and other patients. It would be very difficult for staff to treat a patient who actively resists being dialyzed and for patients to witness another patient being "forced" to be on dialysis. Doing so would likely affect the unit's morale and the daily functioning of the staff.

These issues raise social workers' moral distress. Yet, the issue that draws the most amount of moral distress is in allocation of scarce resources, in this case the social worker's limited work time. In an ideal world, a social worker would not have to restrict the time and effort spent with one patient to assist another. Sadly, this does not reflect reality. Every extra minute spent with Florence saps time and energy out of my other consultations. How much time and resource is adequate to say that the team has done its "due diligence"? Other ethical questions to which I have still not found the answers:

- Is allowing her to die infinitely worse than restraining her thrice weekly for dialysis?
- What is the *good* we are trying to achieve?
- Can life sometimes be worse than death, in all its finality?

## CONCLUSION

Writing this article was a way to provide a closure for my wanting to linger back to the encounter, playing it in my mind over and over again and checking her clinical chart to make sure I have not missed anything important to add to the story. The discharge notes read: "End Stage Renal Disease. Failure to consent to HD." Does this tell her story or mine?

If I were to reflect, what made this particular case different? I would honestly have to admit that my interaction with Florence made me stop and think. We get preoccupied, rightfully so, with the instrumental items, such as ensuring that patients have the benefits they need and the information they require about housing, their illness and their treatments. In the end, it can become mechanical or routine. Florence had housing, financial benefits, medication coverage and a family that was supportive, yet she refused dialysis. Florence was consistent; she was determined to follow whatever she felt was best for her even though she was told repeatedly that she was going against medical advice.

What did I learn from working with Florence? I would have to say this case reminded me of what I was taught: The first principle of social work is to respect and value the patient. This case reinforced my social work values and ethics, including the right of self-determination and Florence's intrinsic value. With this in mind, I was able to continue working on Florence's behalf, to make certain that her wishes were heard even though it meant going against the rest of the medical team. The apprehension and hesitation about working with Florence is gone.

The process to reach this stage involved several consultations with fellow renal social workers, some renal team members, the hospital bioethicist who has a social work background and a clinical ethics fellow. Another form of consultation involved participating in a case presentation at the Joint Centre for Bioethics, University of Toronto. Membership of the group consulted included bioethicists with from diverse backgrounds, including social workers, physicians, philosophers and a lawyer. The presentation provided me with the opportunity to gain a collective perspective from different disciplines on Florence's case. I am cognizant that it is not the norm to have the chance to consult with such a wide range of professions. Consultations in general and this one in particular provided me with valuable peer support, guidance and a "sounding board" for ideas about how to work with patients/clients.

The other component to the process, which is unique to social work, is self-reflection, a soul searching. Early in the education to become a social worker, one is taught to be objective and neutral when working with patients/clients. However, it is also important to be aware of one's biases and values, and how these biases and values can influence the working relationship with the patient/client. Social workers are fully aware that they will encounter patients who may make decisions with which they may not agree. These decisions can be a struggle within the social worker, but it is important to remember that there is no right or wrong answer when dealing with people's lives. To work through this struggle, I remind myself that I am here for the patient. I understand that as a member of the medical team my job is to persuade the patient to follow the proposed treatment plans. However, the priority should be the patient, especially if the patient's wishes were not being heard. My priority needs to be Florence. She needs to be provided with support, not judgment, and a voice when others may not have given her one. Once I came to this realization that my role as Florence's social worker is to make certain that her voice is heard loud and clear, the ethical dilemma subsided.

## EPILOGUE

A few months after the conclusion of this case study, I met with Florence on admission to the emergency unit after a bout of severe symptomatic uraemia. She finally agreed to a trial of HD. She is currently on hemodialysis and attending clinic for her care. There is no clear plan for her future medical care but to take each hemodialysis session at a time. Will she continue to come in for her life-sustaining treatments? Of one thing I am certain, Florence continues to be my patient and I continue to be her social worker, her advocate. Thus, Florence's story continues.

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# The Renal Caregiver Burden Scale: Phase One

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*Caregiver burden is becoming more important as the aging population becomes larger. This growth applies to caregivers involved in chronic illness management in general, and chronic renal disease in particular. The purpose of the present study was to create the Renal Caregiver Burden Scale (RCBS) and establish basic measures of its reliability and validity. In a preliminary test for the new measure, seven master's level renal social workers from various clinical settings across the country interviewed 52 voluntary dialysis patient caregivers. The measures used were thought to be associated with the construct of burden. A Cronbach alpha analysis yielded a reasonably high internal consistency reliability of 0.84 for the 16-item RCBS. The measure also correlated highly with the Zarit Burden Interview at 0.72 and the Center for Epidemiologic Studies Depression Scale depression scale at 0.70. Recommendations for further refining and validation of the measure with a larger sample are discussed. The relatively high degrees of reliability and validity for the first outing are encouraging, although 2 of the 16 items need restating due to ceiling and basement effects.*

## INTRODUCTION

In health care, a caregiver is typically a family member or a friend (Buhse, 2008). They experience greater levels of stress and a lower quality of life compared to non-caregivers (Devor & Renvall, 2008; Piira, Chow, & Suranyi, 2002). Caregivers assist patients with tasks such as bathing, eating, housekeeping, medications and shopping (Buhse, 2008; Foster, Brown, Phillips, & Carlson, 2005). Due to the chronic nature of many diseases and conditions, family members may be called on to provide long-term, even lifelong, assistance to their disabled relatives (Cummings & MacNeil, 2008).

## CAREGIVER BURDEN

Caregiver burden is a common response to the problems and challenges associated with caregiving (Buhse, 2008; Cummings & MacNeil, 2008). Generally, caregiver burden encompasses physical, psychological and emotional responses, and can also include factors such as financial stress (e.g., from out-of-pocket medical expenses) and a secondary premature institutionalization of the patient. In addition, excessive caregiver burden can result in premature aging, increased caregiver mortality rates and depression (Devor & Renvall, 2008).

The study of caregiver burden has been extensive, with many studies on burden associated with caring for friends or relatives dealing with mental illness, physical illness and advanced age. Caregivers report that they have emotionally stressful duties, suffer from mental or physical health problems resulting from their caregiving responsibilities and spend less time with other family members (Foster et al., 2005). When compared to the general adult population, caregivers are more susceptible to health problems and have increased rates of depression, psychotropic medication use and self-reported stress symptoms. For example, a study by Matire et al. (2008) found that greater burden may lead to expressed emotions, such as criticisms and hostility, thus negatively impacting patient care.

Buhse (2008) and Cummings and MacNeil (2008) each described caregiver burden as both objective and subjective. Objective burden is a tangible, observable and concrete cost taken on by the caregiver as a result of caring for the patient. Subjective burden is the perceived costs (i.e., the extent to which the caregiver is bothered by the responsibilities of caring for the individual) and the positive or negative feelings associated with the care. The perceived burden may include feelings of conflict and loss as a result of the changing roles within the relationship (Buhse, 2008).

There appears to be a high correlation between depression and caregiver burden (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Sepulveda, Whitney, Hankins, & Treasure, 2008). The more burden a caregiver feels, the greater the levels of depression. This can lead to problems for the caregiver, especially for informal caregivers, who tend to underutilize support systems (Devor & Renvall, 2008). Caregivers need support for themselves while still wanting to support their loved ones. They often experience feeling overwhelmed, neglected and ignored, which in turn leads to greater burden (Buhse, 2008). Research indicates that higher levels of family support are associated with lower psychological distress among caregivers (Cummings & MacNeil, 2008). Yoon (2003) suggests that, when possible, family counseling or some other family-focused service is needed to increase a caregivers' emotional support from other family members.

Caregiving tasks and their associated stress levels can lead to compromised health (Butler et al., 2005). Caregivers may become consumed by the strain of caring for the patient and how this strain impacts their own or another family member's health (Sepulveda et al., 2008). Health consequences are not only psychological but also physical. Butler et al. (2005) identified that caregivers can exhibit decreased immunity, increased risk of serious illness, slower wound healing rates, greater cardiovascular reactivity and increased mortality risk.

### *Chronic Renal Failure and Caregiver Burden*

There has not been much study on kidney patient caregivers. Caregivers can experience a sense of confinement, revolving around the patient's need for hemodialysis treatment, always having to be available, always having to plan their day and continually being preoccupied with the disease (Ziegert & Fridlund, 2001). Caregivers can experience a sense of social isolation, concluded from "less leisure time, reduced social contacts, a restrictive time table, and a sense of missing out on the good times" (Ziegert & Fridlund, 2001, p. 237). Increased fatigue experienced by caregivers, especially when caring for chronic renal failure, has been explored only to a minimal degree (Schneider, 2004). Alvarez-Ude et al. (2004) found that physical health was more affected in younger caregivers, who perceived a higher burden of work. In this study, the authors also found that mental health was affected more in those perceiving a lower social support system or those caring for patients with remarkable mental health problems reporting a higher subjective burden. Caregiver burden has also been shown to be associated with depression (Alvarez-Ude et al., 2004; Schneider, 2004).

## PURPOSE

The study was a measurement study. Building on earlier work by the author (Schneider, 2004), the purpose was to establish initial measures of reliability and validity for the Renal Caregivers Burden Scale (RCBS; see Appendix A). The RCBS was administered to an ad hoc sample of 52 first-degree dialysis caregivers. Acceptable reliability and validity measures were established with a Cronbach alpha and through correlations with existing well-established measures of both burden and fatigue.

## METHODS

### *Sample*

Subjects were voluntary first-degree dialysis patient caregivers and were sampled as available from seven participating dialysis centers nationwide. The eligibility criteria were that each respondent had to be alert and oriented, be non-alcoholic or drug abusing, live with the patient or be in regular daily contact with the patient and be primarily responsible for at-home care. Thus, residents of long-term care facilities were ineligible. Of those approached, 15 subjects declined to participate. No reasons were given. The average treatment length for the sample was 44.1 months.

The research proposal was first approved by the University of Northern Iowa Human Subjects Committee. A query was then sent to the Council of Nephrology Social Workers members via their listserv. Seven of the licensed master's level renal social workers responded positively. Each interviewer had completed the federal human subjects' protocol online. A permission to participate form was obtained from the director of each agency. The health quality of life (HQOL) scales used in the study were reviewed by the social worker and director of each center. After each voluntary caregiver signed an informed consent form, he/she completed a battery of HQOL measures and returned them to the staff social worker. The demographic variables are reproduced in Table1. None of the patients had had a kidney transplant.

## MEASURES

**Table 1.**

Demographic and Treatment Variables *(N = 52)*

| Variable | Caregiver | Patient |
|---|---|---|
| Age | 64.1 (12.5) | 70.5 (12.7) |
| Sex M/F | 34/17 (32/65%) | 29/23 (56/44%) |
| Race | Asian: 3 (5.8%) | Asian: 3 (5.8%) |
| | Black: 4 (7.7%) | Black: 4 (7.7%) |
| | White: 43 (82.7%) | White: 43 (82.7%) |
| | Other: <4% | Other: <4% |
| Total Months Treatment | — | Mean 44.1 |
| Relationship | Husband: 14 (26.9%) | — |
| | Wife: 23 (44.2%) | — |
| | Co-habitator: 1 (1.9%) | — |
| | Father: 2 (3.8%) | — |
| | Mother: 1 (1.9%) | — |
| | Son: 3 (5.8%) | — |
| | Daughter: 7 (13.4%) | — |

### *Center for Epidemiologic Studies Depression Scale*

The Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) is a well-known measure of depression. The content of its 20 items was gleaned from previous items used to measure depression, such as those used in the Beck Depression Inventory (Beck, 1972) and the Zung Depression Scale (Zung, 1967). Each item is scored from 0 to 3 as a frequency of a complaint for "the past week." The conceptual components include: feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite and sleep disturbance. Four items are worded in the reverse direction to reduce the "yeah saying" threat to validity. The CES-D was chosen for its reliability and validity in assessing degrees of depression that may be associated with burden since depression is intricately associated with burden.

### *Zarit Burden Interview*

The Zarit Burden Interview (ZBI; Zarit, Reever, & Bach-Peterson, 1980) is a 29-item interviewer-administered questionnaire designed to assess the degree of burden perceived by caregivers of people with senile dementia. In the ZBI, items were selected based on clinical experience with caregivers and fall into five categories: health, psychological well-being, finances, social life and relationship with impaired person. Twenty- and 22-item versions have undergone psychometric testing (Zarit, 1980; Zarit et al., 1986); a 22-item version also has been developed. The instrument has also undergone psychometric testing in Hebrew, Spanish and Japanese.

The ZBI was chosen to detect convergent validity with the new RCBS because it has high reliability and validity in repeated administrations (Zarit, 1980) and because the burden experience by caregivers of Alzheimer's disease patients is not unlike the burden experienced by caregivers of chronic renal patients.

Throughout the literature on burden, there is debate about the importance of subjective vs. objective measures. Assessing subjective burden involves more uncertainty than assessing objective burden (Robinson, 1983). For this reason, the ZBI was chosen because it is known to assess objective burden or burden that can be operationalized externally.

### *Renal Caregiver Burden Scale*

The RCBS was created for this study. The social worker interviewers, each of whom has renal social work experience, collaborated with the author in creating the items for the measure. These clinicians, including the author, were aware of the areas of burden experienced by the kidney patient caregivers and suggested items to be included in the measure accordingly. Thus, content validity was established. While none of the 29 items in the ZBI were reproduced verbatim, the elements of burden addressed by the ZBI (i.e., health, psychological well-being, finances, social life and relationship with impaired person) were included in the RCBS with a unique focus on the renal caregiver. The submitted items were compiled in random order. Items 3, 9 and 15 addressed health; items 2, 6, 7 and 14 addressed psychological well-being; item 11 addressed finances; items 1, 10 and 13 addressed social life; items 4, 5, 11, 12 and 14 addressed relationship with impaired person; and finally item 5 was added to address general fatigue.

Originally there were 17 items, but one item (item 8) was dropped due to a reduced Chronbach alpha when included with the other 16 items. Item 8 also had a higher variance than all the other items in the measure. Each item is a 5-category Likert-style item that asks for degree of agreement with statements. The responses range from "not at all (agree)" to "strongly agree." Four of the items were reversed coded. In the end, higher scores (range 16–80) represent greater burden. See Further Analysis and Refinement for analyses correcting shortfalls in the present RCBS.

## ANALYSIS AND RESULTS

First item-total correlations and item analyses were conducted (Table 2). While half of the items were significantly skewed, all items correlated with the total score significantly. Increasing the number of subjects can decrease statistical significance, thereby improving the usefulness of an item. Two items in particular were, however, remarkably skewed. For item 7, "I am angry that not following doctor's orders led to ___________'s kidney failure," 37 of 52 (69.8%) responses scored 1 on the 5-point Likert item. For item 10, "I can't do all the things I used to do," 82.1% responded with either a 4 or 5. Because of such basement/ceiling effects these two items must be reworded to make each item more normally distributed.

The RCBS was tested for reliability. As mentioned, the 16 items were analyzed via Cronbach alpha with a reasonably high value of 0.84. The second part of the scale analysis was an attempt to establish construct validity by correlating the RCBS with the CES-D and the ZBI. The RCBS correlated significantly at 0.001 with the CES-D ($r = 0.637$). This follows because depression is conceptualized as an element of *burden*. For example, in this study the CES-D and the ZBI correlated moderately at 0.470, also at 0.001. The correlation of the RCBS with the ZBI at $r = 0.720$ ($p = 0.001$) suggests concurrent validity. The ZBI is considered a standard in burden measurement, so high correlation is encouraging.

The preliminary tests for reliability and validity of the RCBS are encouraging. The next stage is to test the measure

**Table 2.**

*Item Statistics and Item-Total Correlations*

| Item | Mean | Variance | Item-Total Correlation |
|---|---|---|---|
| KD01 | 2.10 | 1.53 | 0.521** |
| KD02 | 3.58 | 1.29 | 0.577** |
| KD03 | 2.31 | 1.57 | 0.680** |
| KD04 | 3.20 | 1.45 | 0.365* |
| KD05 | 2.04 | 1.37 | 0.315* |
| KD06 | 2.94 | 1.59 | 0.525** |
| KD07 | 1.60 | 1.12 | 0.279** |
| KD09 | 3.15 | 1.44 | 0.700** |
| KD10 | 4.04 | 1.07 | 0.595** |
| KD11 | 2.60 | 1.47 | 0.567** |
| KD12 | 2.33 | 1.56 | 0.605** |
| KD13 | 2.92 | 1.43 | 0.597** |
| KD14 | 3.00 | 1.46 | 0.341* |
| KD15 | 3.04 | 1.41 | 0.507** |
| KD16 | 2.00 | 1.01 | 0.514** |
| KD17 | 2.31 | 1.29 | 0.498** |

$*p \leq 0.05$; $**p \leq 0.01$.

on a larger, more diverse group of caregivers. The results are expected to be encouraging because, while not randomly sampled, the subjects in the present study are not particularly unrepresentative of the typical adult dialysis patient.

## FURTHER ANALYSIS AND REFINEMENT

While there were only 52 subjects, they were enough to conduct an internal consistency analysis with guarded results. To establish a measure of validity, the 52 yielded moderate to high correlations with the CES-D and the ZBI, but 52 is a small number and limits the number of statistical analyses that can be performed, such as an exploratory factor analysis. The sample needs to be increased appreciably to conduct further analyses. Also, subjects should be sampled purposively to represent the actual distribution of caregivers in the population.

The reversed-coded items can threaten the validity of the total measure because they may artificially create factors unintended in the single-construct measure (e.g., a methods factor; Rodebaugh et al., 2004). These items will be reverted back to the original in a subsequent administration of the measure. Analyses for individual items, including item-total correlations are reported in Table 2.

Scores for the measure were normally distributed. The mean was 43.1 (11.4). The item mean was 2.70 (0.65). While half (8) of the items were skewed to some degree, increasing sample size is likely to reduce a number of skewed items. However, as stated previously, items 7 and 10 were highly skewed and need to be rephrased to remove any basement and ceiling effects.

While the measure tested in this study shows promise, until further detailed analyses with a larger sample size and recoded items are completed, the final usefulness of the measure is unknown.

## CONCLUSION

Increased life expectancy and prevalence of chronic conditions has led to an increase in the number of older individuals being cared for in the home by family members (Alvarez-Ude, Valdes, Estebanez, & Rebollow, 2004). Cummings and MacNeil (2008) state that “family support and care is an important element” allowing patients to “avoid living behind the walls of institutions.” In most cases, similar to the mentally ill, patients fare better in their own environments.

When looking at family caregivers who report a greater burden than others, Martire et al. (2008) report that there is less support for older relatives in regard to their symptoms and management of their illness. That is, families who are burdened may not have the psychological and concrete resources to care for their family member. Administering the RCBS once it is refined may identify caregivers who are at risk for the consequences of caregiver burden in addition to being compromised in their caregiving activities.

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## APPENDIX A

**Author's Note:** The scale presented below represents a preliminary measure of real caregiver burden. Additional psychometric testing is needed to assess the measure's validity and internal consistency.

### *Renal Caregiver Burden Scale*

Instructions: Please rate each of the following items using a 5-point scale, where 1= not at all, 2 = somewhat disagree, 3 = neutral, 4 = somewhat agree, and 5 = strongly agree. For items that contain underlining ("______"), please use the patient's name in this location to complete the sentence. You do not need to write in it.

1. There are others who should be helping me with patient care.

2. My level of distress has increased since ____________ began treatment for kidney disease.

3. My health has worsened since ______________ became ill.

4. I am frustrated when ____________ does not follow medical directions.

5. Transportation to treatment and doctors' appointments is a source of stress.

6. Time management is a source of frustration.

7. I am angry that not following doctor's orders led to ___________'s kidney failure.

8. Our finances are good since_______________ began treatment.*

9. I am physically exhausted.

10. I can't do all the things I used to do.

11. Finances related to treatment are a source of stress.

12. __________ does not seem to appreciate all I do for him/her.

13. I spend enough time with others.

14. Sometimes I say things to __________ that wish I had never said.

15. I sleep well at night.

16. We laugh together.

17. ____________ doesn't consider my feelings.

---

*Item deleted

# Case Study: Handling the $5,993 Hemodialysis Treatment

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*Thanks to Medicare and private insurance, citizens and residents in the United States seldom have to worry about going bankrupt when they need renal replacement therapy. This case, however, describes what could have been an exception. When an uninsured, low-income patient with significant assets landed at an outpatient dialysis center, he was charged thousands of dollars per treatment. The nephrology social worker struggled with the dilemma of how best to advise the patient regarding his financial options. His advocacy interventions resulted in the patient receiving a substantially reduced rate. This article discusses this case and the national system of funding dialysis, which consistently puts financial pressure on providers and the uninsured.*

## PSYCHOSOCIAL SUMMARY

Mr. "Bucks" was a single Caucasian male in his late-50s. He lived with and cared for his father who was in his mid-90s. Through a career of modest paying jobs and frugal discretionary spending, Mr. Bucks had managed to save more than $250,000, which he estimated generated a yearly income of less than $5,000.

Mr. Bucks recognized the importance of health insurance, and therefore chose COBRA with what he described as a "very good" national plan when he was laid off by his employer. A history of hypertension, atrial fibrillation and mid-stage chronic kidney disease (CKD) convinced Mr. Bucks to put himself under the care of a nephrologist for almost 5 years. During the 18-month period in which he was enrolled in COBRA, his premiums increased from $450 to $550 per month, which he willingly paid because of the excellent benefits. For example, he noted that 2 micrograms of oral Hectoral alone without insurance would have cost about $620. With COBRA, the full monthly copay for this medication as well as multiple others, including Procrit, was only about $130.

During the COBRA period, Mr. Bucks found another job with a national retailer and considered joining its group health plan to end the running time clock on COBRA. However, the employer had a 6-month probationary period in which new employees could only join a "bridge" medical plan. While the premium was about $360 a month, the employer instituted a $1,000 cap on pharmaceuticals during this 6-month period. Mr. Bucks calculated that he would lose thousands of dollars by switching.

Mr. Bucks' COBRA insurance terminated on October 9, 2009, but the next few days for him were an atypical blur. At 3 a.m. on the day after the COBRA insurance terminated, Mr. Bucks was taken by ambulance to the local hospital, unconscious and suffering from a severe upper respiratory infection. He regained consciousness a few days later. The physical stress on his body during this episode tipped him into Stage 5 CKD.

## THE PRESENTING PROBLEM

Similar to most new dialysis patients, Mr. Bucks had various challenges to face. He had been at Stage 3 CKD for some time, and while he had viewed dialysis as an eventuality down the road, he was initially disheartened by how quickly his respiratory infection and acute hospitalization had taken him there. Having had the benefit of nearly 5 years of nephrology care, he was educated on different treatment modalities and received a fistula in his left arm in the autumn 2005. However, the fistula never worked. Consequently, when it was determined that he would need dialysis emergently, a permacath was placed.

**Figure 1.** Mr. Bucks' Itemized Bill for His First Outpatient Hemodialysis Treatment

| DATE | PROCEDURE | UNITS | DIAG | CHARGE |
|---|---|---|---|---|
| 10/27/09 | -Tx High Flux-Cath | 1.00 | | 2,125.00 |
| 10/27/09 | -EPO < 10,000 units | 600.00 | 285.21 | 960.00 |
| 10/27/09 | -PTH Intact (Plasma) | 1.00 | 588.81 | 511.82 |
| 10/27/09 | -Zemplar 1 Mcg | 4.00 | 588.89 | 305.60 |
| 10/27/09 | -Hep C Virus AB | 1.00 | V15.85 | 176.86 |
| 10/27/09 | -Hep B Surface AB | 1.00 | V15.85 | 133.21 |
| 10/27/09 | -Heparin-Pork 1000 Un | 25.00 | E934.2 | 132.00 |
| 10/27/09 | -Hep B Surface AG | 1.00 | V15.85 | 127.90 |
| 10/27/09 | -Hemoglobin, A1C | 1.00 | 250.42 | 120.29 |
| 10/27/09 | -UIBC | 1.00 | 280.00 | 108.28 |
| 10/27/09 | -HDL Colesterol | 1.00 | 272.0 | 101.39 |
| 10/27/09 | -CHR (Recticulocyte Hg) | 1.00 | 285.21 | 99.32 |
| 10/27/09 | -Admin Supply Injection | 2.00 | E934.2 | 84.52 |
| 10/27/09 | -Iron | 1.00 | 280.0 | 80.23 |
| 10/27/09 | -Triglycerides | 1.00 | 272.0 | 71.27 |
| 10/27/09 | -CBC W/O Differential | 1.00 | 285.21 | 69.21 |
| 10/27/09 | -ALT- SGPT | 1.00 | 573.9 | 65.62 |
| 10/27/09 | -Alkaline Phosphatase | 1.00 | 588.89 | 64.00 |
| 10/27/09 | -Calcium, Total Serum | 1.00 | 588.89 | 63.83 |
| 10/27/09 | -Creatinine. Blood | 1.00 | 585.6 | 63.38 |
| 10/27/09 | -Albumin, | 1.00 | 263.9 | 61.40 |
| 10/27/09 | -Bicarbonate | 1.00 | 276.2 | 60.60 |
| 10/27/09 | -Phosphorous, Serum | 1.00 | 588.89 | 58.81 |
| 10/27/09 | -Chloride, Blood | 1.00 | 276.2 | 56.92 |
| 10/27/09 | -Potassium, Serum | 1.00 | 276.7 | 56.92 |
| 10/27/09 | -Sodium, Serum | 1.00 | 276.9 | 54.15 |
| 10/27/09 | -Cholesterol, Total | 1.00 | 272.0 | 53.96 |
| 10/27/09 | -Admin Supply Injection | 1.00 | 588.89 | 42.26 |
| 10/27/09 | -Admin Supply Injection | 1.00 | V74.1 | 42.26 |
| 10/27/09 | -Admin Supply Injection | 2.00 | 285.21 | 42.26 |
| | Total Charges | | | $5,993.27 |

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During the psychosocial intake, Mr. Bucks stated that he knew he would not be eligible for state assistance because of his savings. He had budgeted about $1,000 a treatment, based on what the hospital social worker and nephrologist had told him. He was informed that his Medicare effective date would be January 1 with in-center hemodialysis, or October 1 with home dialysis. The patient decided to pursue in-center hemodialysis. The patient was informed that he lived in a state where the law mandated insurance companies could not discriminate based on pre-existing conditions for certain Medigap plans.

Mr. Bucks' first bill from the dialysis center arrived about 10 days after his first treatment. For three treatments, the total cost was $14,581.43 (an average of $4,860.47 per treatment). Because his first treatment contained initial lab work, its cost was $5,993.27. The charges from this first day are reproduced in Figure 1, which includes the procedure, diagnosis code and costs. Mr. Bucks presented the bill to the clinic manager and social worker with distress, anger and questions about what others were paying for treatment.

## THE ENVIRONMENT

Having worked with dialysis patients for 14 years, I always considered myself fortunate to be able to assist a population that has so many resources available. Much has been written about the sorry state of access to American health care compared with other industrialized democracies. America has 47 million uninsured, a majority of whom work full-time and endure higher costs for poorer outcomes (Park, 2008). Since 1973, the year after Congress established the Medicare End-Stage Renal Disease Program to pay for dialysis, kidney patients in the United States have enjoyed increasing access to care (Egan, 2000). Private biotech companies, such as Amgen, have a long history of generosity with their life-enhancing products for people with limited means. The large dialysis organizations (LDOs) have indigent programs to document uninsured or underinsured patients and then take a partial tax credit against the bad debt. The LDOs also provide millions of dollars of funding through the American Kidney Fund to assist in paying insurance premiums for Medicare, Medigap and COBRA plans for patients with limited means. This is a win-win for the patient and the LDOs, albeit a drain on profits for the insurance industry. For example, in the author's state, a Medigap C plan costs about $200 per month but often pays more than $500 per month for the 20% of dialysis services not covered by Medicare.

The ample access to care for dialysis patients is not without a bizarre and somewhat precarious nature of funding. With respect to Medicare payment for dialysis, the U.S. Government Accountability Office has stated:

> … payments did not meet costs for small facilities. In addition, composite rate payments, intended to cover the costs of dialysis services associated with a treatment, including nursing, supplies, social services, and certain laboratory tests, were 11 percent less than the costs of providing those services, while payments for separately billed drugs, drugs not included in the composite rate, exceeded the costs of those services by 16 percent (2004).

More recently and specifically (Conte & Fabregas, 2009), one LDO stated "it spends about $289 per treatment but receives about $250 from Medicare." In the same news article, the vice president of another LDO said, "We need to identify … certainly, new patients with insurance. That's what allows us to treat all patients. This private subsidy really allows the whole model to work." Because of the disproportionate monetary value of these payments, the LDOs have developed special customer service paths to retain and develop that portion of their business. Additionally, because the Coordination of Benefits Rule relegates almost all patients to Medicare primary 33 months after initiating hemodialysis, companies are under unceasing financial pressure to find new commercial patients (Conte & Fabregas, 2009).

## THE INTERVENTION WITH ANALYSIS

Potential dialysis patients without any insurance arrive at my local hospital infrequently. When it does happen, the social work team at the hospital is prompt to evaluate and usually helps the patient apply for state Medicaid. In these situations, the responsibility for accepting the patient into our clinic falls to the Administrator of Functions (AF). According to the job description, in the context of promoting excellent patient care, an important part of the AF's position is to practice cost-containment strategies, maintain profitability and grow business. When a patient does not have insurance, the AF has the option to reject admission as ultimately the AF is responsible to the Executive Vice President (EVP) for justifying the financial results of their area. Our AF accommodates staff needs and patient wants within the philosophy of a for-profit corporation that embraces austerity. He has a long history of accepting patients without insurance when it appears likely that insurance will be forthcoming.

Speaking with my social work colleague at the hospital, I was surprised when I heard about Mr. Bucks' assets because we both knew he would not qualify for state assistance. I emailed my AF that from a financially risk-averse perspective, he might want to proceed cautiously. For better or worse, I was trying to protect my AF and company from incurring bad debt. Knowing the hospital had a legal obligation to treat the patient, I preferred to let it bear the burden of financial risk until more details emerged. I shared with the AF what I had learned from my hospital colleague. The AF then gave financial approval for the patient to be admitted.

In my psychosocial assessment, I discussed his future insurance effective dates with each modality contingency. I was relieved that Mr. Bucks expected to pay about $1,000 per treatment in the short term and that he perceived it would not cause him undue financial distress. I informed the AF that it was my impression that he would pay his $1,000 bill per treatment on a timely basis. The AF noted that he thought Mr. Bucks' price per treatment would be considerably more since it was based on the "standard rate." My concerns for my company losing money were quickly replaced by dread for Mr. Bucks' financial well-being.

The AF indicated that he was uncertain of the exact amount of the standard rate. I purposely did not pursue asking the standard rate price because in my social worker role I had no desire to deliver nor defend the bad news. I realized that Mr. Bucks would be receiving a bill fairly soon. In my own research on the company's website, I found no standard rate prices. However, I did find that rates were set by a strategic payer committee and could be modified by senior level executives. I also asked my area's Billing Coordinator (BC) if she knew the standard rate price because she is responsible for nearly 1,300 patients. She stated that neither she nor her department had the information. I was perplexed by the lack of transparency of the standard rate. She had, however, two self-pay patients who essentially paid nothing because they were indigent and close to obtaining Medicaid.

Coincidentally, on November 2, I learned that my clinic had received a request for one treatment from a patient in the Caribbean who had expressed a desire to visit. When I asked what this patient would be charged, I was quite surprised to learn that our company had internally published rates that could be shared for visiting patients to our clinics. I obtained the official document of published rates for visitors. The rates were all-inclusive per treatment. Stratified by patient origin and destination, they varied, with the minimum more than $300 and the maximum less than $900. The Caribbean patient qualified for the high end but he prospectively called a competing clinic that undercut our rate by 50%. This time, our company chose not to match the rate. I feared this response was a harbinger of the response Mr. Bucks would receive. When Mr. Bucks brought us his first treatment bill of $5,993 and piercing questions, my composure was tested, as I initially was uncertain of how best to help him.

I pondered the core question of this case: As a loyal company employee and conscientious clinical social worker who abides by our professional code of ethics, what should I do in a situation where the interests of my company seemed to conflict with the patient? Consulting the *National Association of Social Workers Code of Ethics* (2008) section 3.09, I found "(d) Social workers should not allow an employing organization's policies, procedures, regulations, or administrative orders to interfere with their ethical practice of social work. Social workers should take reasonable steps to ensure that their employing organizations' practices are consistent with the *NASW Code of Ethics*." So I asked myself, was it ethical to allow my patient to pay $5,993 for a dialysis treatment? He certainly had the money and my company had behaved entirely legally. American citizens go bankrupt from health care expenses on a fairly regular basis. According to Himmelstein, Thorne, Warren and Woolhandler (2009), "Using a conservative definition, 62.1% of all bankruptcies in 2007 were medical." But I, and my clinic manager, felt troubled that he was being charged close to 10 times what we knew from experience our LDO considered a good commercial rate.

I reread my company's values statement. Ultimately, the word that I had trouble reconciling was "integrity." Had the patient known ahead of time the cost of his treatment in the context of the prevailing rates, I think I would have felt fine. But he came to us with no accurate knowledge of the economics of dialysis, including the intense competition among companies for commercial-sized reimbursement. So while his environment (i.e., our dialysis center) was saving his physical life, the cost was as quickly killing his economic life. My social work training told me, at the very least, I needed to educate the patient about the market for dialysis consumption so that he could make the best choice for himself.

The next day, I met with Mr. Bucks and gave him a quick education as we read my company's value statement verbatim. Proud of this credo, I used it as a platform to increase transparency. I then explained about reimbursement rates, including Medicare, commercial and what I had recently learned about self-pay visitors. After he got past his anger regarding his bill, he volunteered that he really enjoyed the service and staff at the clinic as well as his physician and asked what he could do to get some relief from what he was being charged. I obtained his permission to discuss the specifics of his situation and bill with his nephrologist. Nephrologists obtain medical privileges to practice at outpatient dialysis centers and typically are not employees of the LDOs.

I showed the itemized bill to his nephrologist who, with some encouragement, decided to speak directly with the AF to ask that the charges be brought in line with the commercial rate he and the patient had been expecting. As a referring physician bringing business into the dialysis center, the doctor acknowledged that the dialysis company had a stake in keeping him, as well as his patients, satisfied.

The next business day, the AF called to let us know that he brought the physician's concern to the EVP. The AF apologized but said that no adjustment would be made—that the standard rate could not be adjusted. This answer was not entirely unexpected because of my earlier experience with the Caribbean patient. The AF suggested that the patient talk to the BC to see whether she had any suggestions. The dialysis company's financial assistance programs are quite generous, but they are designed for people with limited income and without substantial savings. From experience, I understood financial relief would not be granted since my patient's liquid assets were so sizable. I asked if we could designate him a visitor for the few months he would be uninsured and implement the internally published visitor rates. The AF said he would check with the EVP. I thanked him. I suggested that the EVP might personally want to gauge the extent of the physician's displeasure and/or prepare for the revenue-reducing possibility that Mr. Bucks would permanently leave our clinic to another offering a more competitive, market-based price. A few days later, the AF stated that he had spoken with the EVP and that Mr. Bucks' price per treatment had been lowered to $475, all-inclusive. The physician, Mr. Bucks and I were elated and thankful.

## SELF-REFLECTION AND CONCLUSIONS

The literature contains research studies about social workers' emotional exhaustion and burnout working with kidney patients (Merighi & Ehlebracht, 2005; Merighi, Browne, & Kennan, 2009). The countertransference I experienced in this case from my mutual goals of serving my patient's and employer's best interests equally well created a cognitive dissonance that affected my thoughts and sleep. Peer consultation from a colleague as well as respected nurse managers helped me to navigate through a choice of interventions. Specifically, the ventilation they allowed helped me to keep my interventions with the patient, doctor and AF calm, objective and ultimately successful.

Lest the reader consider my interventions as overly altruistic or sentimental, as a shareholder in my company I acknowledge that my appetite for profit is as sizable as anyone's. It would be hubris to think I could do a better job setting price points than my company's experts. I also, in hindsight, understand the short-term business benefit of charging visitors a transparently lower rate than permanent patients in an opaquely priced market. I am proud of the exceedingly strong ethics and compliance policy my company has. In fact, had Mr. Bucks expressed no concerns about paying the thousands of dollars per treatment, I would have let him. But his vocal dissatisfaction with the bill combined with his lack of knowledge about dialysis market dynamics compelled me to try to help. I felt much better after I educated him knowing that he could exercise his right to self-determination as he saw fit.

Putting myself in management's shoes, I now clearly see how providing dialysis services to Mr. Bucks represented an opportunity to earn much-needed resources. Similarly, as the licensed clinical social worker, I was obliged to advocate for the overall well-being of my patient. That our respective functions might at times operate at cross-purposes should not be surprising. As the checks and balances of our successful government can occasionally make democracy a bit messy, so too can the competing goals of all the stakeholders in the dialysis center. The ongoing test then for a nephrology social worker who aspires to be maximally effective is to work in a way that builds all relationships, or at least does not harm them. This challenge may be one of the factors responsible for emotional exhaustion.

I believe that Mr. Bucks might have received a competitive price sooner had management talked with or met him. Like most large companies, the relative insulation leaders have from customers/patients is both an asset and liability. On the positive side, the complex and difficult daily decisions our corporate leaders need to make to ensure our long-term viability might be harmed if they were overly concerned with the minutiae of patients' daily lives. Yet on the other side, our leaders' decisions often have major implications on the lives of our patients. It can serve the customer and company poorly to have a feedback loop stretched beyond a point where the message is lost towards the top. In a perfect world, those of us at the clinic level bolster the message so that leadership receives patients' feedback intact. But speaking truth to power is not for the faint of heart and it is usually less stressful for line workers on the floor to remain silent.

This case also serves as an important reminder of how differently the health care market functions from other markets of goods and services. Theorists or pundits who express a belief that free-market economics alone can serve patients well fail to realize that ill people are unlike other consumers with the time and flexibility to shop based on published prices. On the contrary, the inability of the sick to shop and the urgency of their need to trust can leave them decidedly disadvantaged or worse, at risk for exploitation.

I find it noteworthy that in the absence of market knowledge, Mr. Bucks would have been willing to pay the $1,000 per dialysis treatment. While he did have time in the hospital to digest this figure, his attitude demonstrates an appropriate appreciation for the value of dialysis. If the government historically underfunds dialysis, we can understand the potential pressure to seek higher commercial payers and cost shift onto individuals like Mr. Bucks who have the means to pay. Dialysis providers make a reasonable argument that these strategies are not only useful, but in fact, essential if they are to maintain the capital to care for patients and build shareholder value. No doubt, Medicare bundling for dialysis set to begin in 2011 will change the renal care financing landscape considerably. Effects as yet to be determined will ripple through the entire dialysis infrastructure.

Shortly after Mr. Bucks began his course of in-center hemodialysis treatment, he received a visit from the home-training nurse about peritoneal dialysis (PD). His training, combined with a reminder about the potentially accelerated start date of Medicare, caused him to reconsider this modality. While our aforementioned intervention had resulted in Mr. Bucks no longer dreading his hemodialysis bill, he still worried greatly about the cost of his two-week uninsured stay in the hospital. But if he transferred to PD before the first day of the third full month of dialysis, his Medicare would be backdated to the beginning of October (B. Witten, personal communication, November 18, 2009), likely covering the start of his hospitalization. He therefore accurately viewed PD as an 80% solution and is pursuing home training at present. Aside from the medical and psychosocial benefits of home dialysis, an immediate Medicare start date can be highly valuable, as this case illustrates. With its potential to empower, patient education around modalities remains one of the most essential tasks that the nephrology social worker and interdisciplinary team can pursue.

In conclusion, this case serves as another example of how social work can function as an important part of the conscience of a dialysis center. Dialysis social workers actualize their company's core values in tandem with their professional code of ethics. As cost pressures continue to increase in the financing of dialysis, opportunities for nephrology social workers to advocate for their patients will remain, if not increase.

## ACKNOWLEDGEMENTS

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# CROWNWeb: Transforming How Nephrology Social Workers Access Patient-Centric Data

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*In February 2009, the Centers for Medicare & Medicaid Services (CMS) launched a web-based data-collection system in an effort to transform the way End-Stage Renal Disease (ESRD) facilities report care provided for their patients. This system, dubbed CROWNWeb, gives Medicare-certified dialysis providers a central database in which clinical and administrative information can be entered. This system is a universal resource that social workers, patient services coordinators (PSCs) and other ESRD Network personnel can use to access near real-time data pertaining to a patient's course of treatment. This key element will also aid CMS and the renal community in their ongoing commitment to improving quality of life for people with chronic kidney disease.*

*This article focuses on the CROWNWeb system's impact as it relates to the duties of social workers and the interdisciplinary team that are outlined by CMS' updated Conditions for Coverage for ESRD Facilities, published April 15, 2008. It analyzes how the system can help the ESRD community as a whole to boost patient care efforts, quality of life and satisfaction with care. In addition, this article delves into how the system is designed to reduce the barriers that social workers and PSCs may face in obtaining key data regarding their patients.*

## INTRODUCTION

To gain access to the CROWNWeb system, users must complete what is known as the "QIPS Account Process." This procedure ensures that all Health Insurance Portability and Accountability Act measures are met, and that only authorized personnel can access the patient-sensitive data within the system. See **www.ProjectCROWNWeb.org** for details regarding the QIPS Account Process.

Neither Centers for Medicare & Medicaid Services (CMS) nor the End-Stage Renal Disease (ESRD) Networks specify which facility personnel should enter data into the CROWNWeb system. Each facility is responsible for selecting personnel who have a high-level understanding of the information needed to properly submit data to CMS and the ESRD Networks. This article focuses on tasks that may be required of social workers in the renal community. It is each facility's right and responsibility to appoint responsible staff for these tasks on an individual basis.

## CROWNWEB OVERVIEW

CROWNWeb is mandated under Section 494.180(h) of CMS' updated Conditions for Coverage for ESRD Facilities (CfCs), which require all Medicare-certified dialysis facilities to submit data electronically—a move away from previous CMS paper-based data-collection methods (Centers for Medicare & Medicaid Services, 2008).

CROWNWeb is CMS' first step in leveraging the benefits of health information technology for the ESRD population, and will aid the agency in receiving more complete and higher-quality data about dialysis patients (CMS, personal communication, June 23, 2009). The system, which allows authorized users to securely submit patient-based data to CMS from virtually anywhere at any time,[1] provides a means of expediting how patient information is reported, thus assisting with some of the requirements placed on social workers and interdisciplinary teams (IDTs) by the updated CfCs. These requirements include being informed of patients' current statuses, including:

- Awareness of admission status.
- Assurance that CMS-2728 Medical Evidence forms are completed correctly.
- Awareness of modality, educational level and vocational rehabilitation status.

## BOOSTING PATIENT CARE EFFORTS

Social workers are recognized advocates for patients at many dialysis units (Browne, 2009). With the CROWNWeb system, social workers are able to continue campaigning for patients' rights and quality of care. They can also demonstrate that the requirement of measuring patients' psychosocial status (mandated by the updated CfCs) has been met because CROWNWeb allows one to enter the number of patients in each facility who completed the KDQOL-36 survey, a validated health-related quality-of-life analysis specifically created to assess the physical and mental functioning of individuals with kidney disease (Browne, 2009).

## REDUCING BARRIERS

CROWNWeb is designed to help reduce the barriers social workers and IDTs may encounter when dealing with patient data procurement. The day-to-day obstacles that are abridged by CROWNWeb include a user's ability to instantly access a CMS-2728 form that was completed at a previous facility and obtain details regarding changes in a patient's treatment modality. Additionally, it provides facilities the ability to work with their respective ESRD Networks to determine if a transfer patient is in a "gap"

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[1] With the exception of scheduled downtime for maintenance.

status. A “gap” patient is an individual who is not currently associated with a facility, within the past 30 days, and is not deceased.

Below are detailed examples of how the CROWNWeb system is purposed to help alleviate the challenges social workers and IDTs may come across when dealing with patient admissions and discharges:

- **Managing admission/discharge status:** CROWNWeb can facilitate patient discharge documentation. The system allows facility staff, including social workers, to log in to the secured website where the data is held and process a patient discharge, entering a reason of “discontinue,” “acute,” “lost to follow up,” or “death” in a matter of seconds.

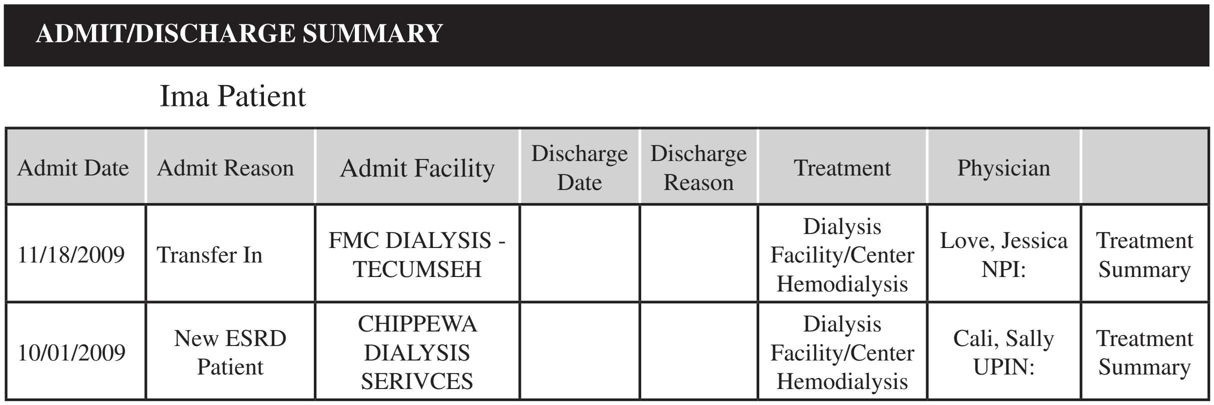
  Involuntary patient discharge is a situation to avoid, and one that the CfCs address directly. Under § 494.70(b)(2) of the updated CfCs, a patient has the right to receive written notice 30 days in advance of a facility terminating his/her care involuntarily, and requires the procedure described in § 494.180(f) be followed. Only in the case of immediate threats to the health and safety of others may an abbreviated discharge procedure be allowed (CMS, 2008). Social workers may enter any involuntary discharge in CROWNWeb once the requirements outlined by the updated CfCs have been met.

  CROWNWeb also keeps a detailed history of a patient’s admission summary, which grants authorized users (those who are affiliated with the patient’s current facility) instant access to admit/discharge records, including the justification for certain types of discharges. The system requires users to explain a discharge if the selected discharge reason is “involuntary” or “transfer.”

- **Tracking transient patients:** CROWNWeb can assist social workers with ongoing patient care efforts by providing a better means of tracking patients after a natural or man-made disaster. In 2005, Hurricane Katrina forced the evacuation and relocation of more than one million residents of New Orleans and the Gulf Coast of the United States. There were almost 6,000 patients with ESRD on life-sustaining dialysis treatment in the region affected by the storm (Anderson et al., 2009). Dialysis centers across the country took in thousands of evacuees who needed treatment, but early on, many patients were still unaccounted for. In an interview with the *Wall Street Journal*, then-acting chief medical officer, Barry Straube, said an “accurate guesstimate” was that “hundreds” of patients were still missing (Jeffrey, 2005). According to the data managers for ESRD Networks 13 and 14, the majority of dialysis patients displaced by Hurricane Katrina were located through the efforts of dialysis providers and ESRD Networks. Even so, it took months to document the status of those displaced dialysis patients.

  Learning from this catastrophe, CMS determined that CROWNWeb should provide facilities and ESRD Networks a common means of tracking all patients who are in a transient status. By default, receiving facilities are not required to admit transient patients if they will be at the unit for less than 30 days and/or less than 13 treatments. However, in the case of a natural or man-made disaster, CMS asks that receiving facilities admit the patients via CROWNWeb as transients with a reason of “disaster.” This enables patients’ original dialysis units, ESRD Networks and CMS to better track patient locations and confirm that the patient is still receiving treatment. The “temporary” facilities can ultimately admit patients as transfers if their treatment exceeds 30 days and/or 13

**Figure 1.** *Sample of Transient Patient Admission in CROWNWeb*



**ADMIT/DISCHARGE SUMMARY**

Ima Patient

| Admit Date | Admit Reason | Admit Facility | Discharge Date | Discharge Reason | Treatment | Physician | |
|---|---|---|---|---|---|---|---|
| 11/18/2009 | Transfer In | FMC DIALYSIS - TECUMSEH | | | Dialysis Facility/Center Hemodialysis | Love, Jessica NPI: | Treatment Summary |
| 10/01/2009 | New ESRD Patient | CHIPPEWA DIALYSIS SERIVCES | | | Dialysis Facility/Center Hemodialysis | Cali, Sally UPIN: | Treatment Summary |

> treatments. See Figure 1 for a sample of how transient patient admission records are captured in the system. In a transient admission, CROWNWeb retains the patient's information at both the original and transient facilities until a discharge is processed from one of the facilities.

In an e-mail interview regarding how the CROWNWeb system may impact the renal community, Beth Witten, MSW, ACSW, LSCSW, of the National Kidney Foundation stated:

> Being able to access CROWNWeb to track where patients are currently receiving treatment following a natural or man-made disaster could help social workers with contacting patients and/or notifying next of kin and any other family the patient has given the facility permission to contact, as well as collaborate with the temporary facility to answer questions of a psychosocial nature to assure continuity of care.

## ADDITIONAL INFORMATION

You can obtain more information on CROWNWeb by visiting the Project CROWNWeb website at **www.projectcrownweb.com**. Register for the CROWNWeb LMS to access tutorials and online courses about completing all of the required tasks in the CROWNWeb system. Information regarding the system is also available at the CMS CROWNWeb website at **www.qualitynet.org** when you click on the ESRD tab.

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# Dialysis Patient-Provider Conflict Reduction: An ESRD Network Quality Improvement Project

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*Trending of complaints and grievances in End Stage Renal Disease (ESRD) Network 5 revealed that a cluster of dialysis units consistently had complaints/grievances in consecutive years. A conflict reduction project aimed at improving conflict management was initiated. Soon after implementation, it became apparent that facilities were struggling with basic quality improvement (QI) concepts, applications and tools. The project's primary focus shifted to assisting facilities in building those skills. Despite variations in competency, each facility improved its QI skill level and all but one experienced a decrease in complaints to the Network. More training and guidance is needed to ensure that facilities are meeting the Quality Assessment and Performance Improvement requirements of the Medicare Conditions for Coverage, thereby potentially increasing satisfaction among patients and staff.*

## INTRODUCTION

Conflict management is a learned skill that, when adequate, can diffuse or even prevent conflict from occurring. The customer service industry understands the importance of training employees to effectively handle difficult or uncomfortable situations with customers, present oneself as caring and communicate well, with the overall goal being to increase satisfaction and prevent conflict from occurring in the first place.

Trending of complaints and grievances in End Stage Renal Disease (ESRD) Network 5 revealed that a cluster of dialysis units consistently had complaints/grievances in consecutive years. It is uncommon for complaints against units to be brought to the Network's attention and highly unusual for a unit to receive such complaints year after year.

At the time the project began, the current ESRD Conditions for Coverage were pending implementation. A conflict reduction project provided an opportunity for facilities to establish a quality improvement (QI) initiative directed at their complaints and patient satisfaction, which was an anticipated Quality Assessment and Performance Improvement (QAPI) requirement of the new regulations.

This project aimed to improve conflict management among eight identified units, thereby reducing by 50% the mean number of complaints per facility received by the Network. The primary question addressed was, "Will the number of complaints received by the Network decline as a result of facilities engaging in QI activities directed at patient concerns?" In addition, the Network was interested to know whether facilities perceived benefit from participating in the project and the materials and resources provided were viewed as helpful.

## LITERATURE REVIEW

Studies in the last 10 years regarding staff training, communication and patient satisfaction were researched. A lack of staff skills and need for ongoing staff education and training on proper interactions with patients is repeated throughout the nephrology literature (Bartlow, 2005; Department of Health and Human Services [DHHS], 2008; Goldman, 2008; Kane, 2009; King & Moss, 2004; Leebov, 2007; Rau-Foster, 2001; Renal Physicians Association & American Society of Nephrology, 2000; Sukolsky, 2003). However, little quantitative research to support this assumption was found. A demonstration project in QI utilizing the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS) tool obtained results showing some positive improvements in participating dialysis facilities, but there were insufficient data to allow for any strong conclusions (Agency for Healthcare Research and Quality, 2007). A computer interactive session at a national meeting conducted by King and Moss (2004) showed that, of the 71% of respondents who indicated frequent involvement in situations with difficult or disruptive patients, only 50% indicated that they were adequately trained to manage the situation.

It is suggested that much of the conflict that occurs in a dialysis unit can be traced to staff communication problems and lack of professionalism (Bartlow, 2005; Goldman, 2008; Leebov, 2007; Sukolsky, 2003; Williams & Kitsen, 2005). Throughout the country, Networks report that the primary areas of concern in patient complaints are related to the patient's perceptions of quality of care and interactions with staff. The Decreasing Patient–Provider Conflict (DPC) National Task Force Position Statement on Involuntary Discharge emphasizes that "… [t]echnicians may inadvertently exacerbate the potential for conflict because they have not had the formal education or professional training of licensed caregivers" (p. 92) and may not be as proficient at diffusing potentially explosive situations (Centers for Medicare & Medicaid Services [CMS], 2008).

It is believed that patients' perceptions of how caring staff members are play an important role in their satisfaction with care, which can lead to conflict when satisfaction is not

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achieved. Poor communication contributes to patient resentment, fear, mistrust and non-adherence (Ambady, LaPlante, Nguyen, Rosenthal, Chaumeton, & Levinson, 2002; Kane, 2009; Williams & Kitsen, 2005). Better rapport can make the patient treatment visit more gratifying for both patient and staff. The creation of a "patient friendly" and "customer-oriented" environment, established with ongoing staff training and QI practices, can lead to improved patient and staff rapport and increased satisfaction (Bartlow, 2005; Rau-Foster, 2001; Schwartz & Batson, 2000; Sukolsky, 2003). With ongoing staff training and development, staff can increase their skill level and gain comfort and competence in dealing with conflict situations, thereby approaching these situations in a more professional manner (CMS, 2008; DHHS, 2008; Goldman, 2008; Kane, 2009; Sukolsky, 2003). When staff members have the ability to prevent and manage conflict, patients gain a greater sense of security and confidence in their care.

## METHODS

To protect facility confidentiality, all participants on conference calls and webinars were provided with a unique code, which made them unidentifiable to other participants. E-mail communication was conducted by blind-copying all recipients. Facilities were also instructed not to return patient-specific information on their reporting to the Network. The project did not require or undergo review by an institutional review board, nor was there reason to secure patient informed consent because research was not being conducted on patients. As a QI activity, the project did not satisfy the definition of "research" as defined by DHHS 45 CRF 46.102(d), which is "… a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge …" Therefore, the regulations for the protection of human subjects did not apply. (See **http://www.hhs.gov/ohrp/qualityfaq.html#q2**.) The Network required targeted facilities to participate under §494.180(i) of the Conditions for Coverage for End-Stage Renal Disease Facilities, which states, "The dialysis facility must cooperate with the ESRD network … in fulfilling the terms of the Network's current statement of work. Each facility must participate in ESRD network activities and pursue network goals."

The project included eight dialysis units from Washington, DC ($n = 1$), Maryland ($n = 1$) and Virginia ($n = 6$) that had at least one annual complaint in 2005, 2006 and 2007. Other units ($n = 16$) that had complaints in the last 2 consecutive years were invited to voluntarily participate if desired. One of these actively participated, bringing the total number of facilities to nine. Nearly 40% of the related complaints were from repeat complainants. Of those, 56% were unique concerns for the complainant (see Table 1).

**Table 1**. *Complaint Characteristics*

| Unit | Total Number Complaints (Number Consecutive Years) | Percent Same Patient | Areas of Concern | Percent Male (Female, Unknown) | Percent African American, (White, Other, Unknown) | Average Age (Range) |
|---|---|---|---|---|---|---|
| A | 3 (3) | 66.7 | Staff<br>Quality of care<br>Professionalism | 100.0 | 100.0 | 78.7<br>(74–81) |
| B | 4 (3) | 75.0 | Staff<br>Quality of care | 100.0 | 100.0 | 67<br>(30–80) |
| C | 5 (4) | 40.0 | Quality of care<br>Professionalism<br>Transfer/discharge | 100.0 | 80.0<br>(20.0, 0.0, 0.0) | 53.8<br>(52–56) |
| D | 16 (8) | 18.8 | Staff<br>Quality of care<br>Transfer/discharge<br>Reimbursement<br>Transient<br>Other | 37.5<br>(62.5, 0.0) | 81.2<br>(6.3, 12.5, 0.0) | 50.4<br>(28–71) |
| E | 5 (3) | 40.0 | Staff<br>Quality of care<br>Other | 40.0<br>(60.0, 0.0) | 100.0 | 49.8<br>(42–62) |
| F | 5 (5) | 40.0 | Quality of care<br>Transfer/discharge | 0.0<br>(80.0, 20.0) | 80.0<br>(0.0, 0.0, 20.0) | 59.5<br>(48–66) |
| G | 15 (5) | 46.7 | Staff<br>Quality of care<br>Professionalism<br>Transfer/discharge<br>Physical environment | 53.3<br>(33.3, 13.4) | 73.3<br>(0.0, 13.3, 13.4) | 60.6<br>(47–84) |
| H | 10 (6) | 40.0 | Staff<br>Quality of care<br>Transfer/discharge<br>Physical environment | 40.0<br>(60.0, 0.0) | 50.0<br>(50.0, 0.0, 0.0) | 61.2<br>(45–80) |
| V | 3 (2) | 66.7 | Staff<br>Quality of care<br>Transfer/discharge | 66.7<br>(33.3, 0.0) | 100.0 | 66.7<br>(52–74) |

As shown in Table 2, of the nine units participating, seven were members of large dialysis organizations, one was a member of a small dialysis organization and one was an independent facility. The number of dialysis stations in the units ranged from 15 to 40. Only one facility was located in a rural area, and it was the second largest facility in the study.

**Table 2.** Facility Characteristics

| Unit | Ownership | Geographic Makeup | Number of Stations |
|---|---|---|---|
| A | LDO | Urban | 20 |
| B | LDO | Urban | 15 |
| C | LDO | Rural | 36 |
| D | LDO | Urban | 41 |
| E | SDO | Urban | 31 |
| F | LDO | Urban | 32 |
| G | LDO | Urban | 26 |
| H | LDO | Urban | 20 |
| Volunteer | Independent | Urban | 17 |

LDO, Large dialysis organization; SDO, Small dialysis organization

The unit administrators were identified as the lead for their unit team. Each unit was expected to assemble a multidisciplinary team of relevant staff. It was anticipated that the team would, at a minimum, consist of the unit administrator, social worker and head nurse.

The project's focus was to provide staff with an understanding of their roles in conflict and to help them develop skills for better management of themselves and the conflict situation. The Network provided technical assistance to participating facilities in the form of QI training (Appendix A), resources, data feedback and individual consultation.

Each unit was provided with unit-specific data, giving as much detail as allowable regarding the complaints/grievances received by the Network, as well as a DPC toolkit (a resource available through all ESRD Networks, developed under a special study CMS contract with the Network Coordinating Center that includes staff in-servicing modules, an interactive training CD-ROM, quality tracking tools and other resources to help staff build and enhance conflict management skills), conflict change statement sheet (Appendix B) and resource list. Because all of the facilities experienced complaints related to quality of care (which are often treatment-related and involve interactions with staff) and all but two experienced staff-related issues, units were encouraged to provide staff training on conflict management techniques, which include effective communication skills, recognition of triggers in self that exacerbate ability to manage conflict, listening skills, professionalism and maintenance of boundaries and resources for continued staff training and conflict monitoring.

Each unit was to assemble a team and develop an aim statement based on review of its initial data, which may have been the information provided by the Network or internal records the unit had already been keeping. The units tracked and trended internal complaints and were instructed to apply QI approaches discussed during webinar sessions. Monthly, each unit provided a report to the Network describing its rapid cycle process, including an annotated run chart demonstrating progress over time and adjustments to processes that were made accordingly. The Network reviewed the submitted reports and provided feedback and guidance with regard to the QI process and the interventions implemented by the facilities.

This project was a one-group pretest–post-test design. Monthly aggregate rates of complaints received by the Network on the participating facilities were tracked and plotted in a run chart. In addition, a questionnaire, which was distributed at the project's conclusion, was designed to determine the usefulness of communication vehicles and project materials provided by the Network.

The quality indicator used to measure the project's success was the average number of patient complaints per facility (mean patient complaints) received at the Network, defined as:

- Numerator: annual number of patient complaints received by the Network and associated with facilities included in the denominator.
- Denominator: number of facilities participating in the conflict reduction project.

In addition, individual dialysis facilities chose quality measures unique to their situations that they tracked and shared with the Network in the monthly reporting.

The baseline period was calendar year 2007, during which time the 8 identified units incurred 15 complaints for a baseline mean patient complaint measure of 1.9. This measure did not change when recalculated to include the addition of 1 volunteer facility, which increased the number of incurred complaints to 17.

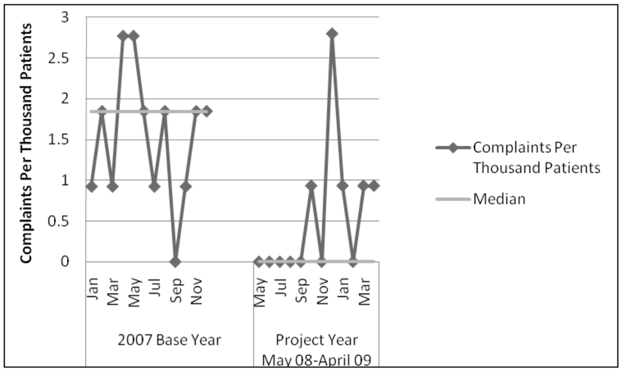
Although the stretch goal was for participants to reduce complaints received by the Network to zero, the immediate goal was to improve their conflict resolution skills, thereby reducing complaints by 50% in the annual period that began 2 months into the project and ran for 1 year (May 2008–April 2009). The Network's goal was to receive seven or fewer complaints per eight units for a mean patient complaint measure of 0.9.

## RESULTS

Soon after the project's implementation, it became apparent that facilities were having difficulty with basic QI concepts, application and tools. The project's primary focus shifted. The goals became to provide facilities with a working knowledge of QI process, establish tracking/trending mechanisms and apply these mechanisms in a plan-do-study-act (PDSA) cycle. (PDSA is a methodology for making changes to improve. It is based on breaking down change into smaller pieces and then testing the change on a micro level and analyzing the results to validate improvement before implementing the process throughout the entire organization.) The original goal of 50% reduction in complaints remained, but became secondary to assisting facilities in putting these QI systems in place.

The number of patients remained stable throughout the study period. During the 2007 baseline period, the participating units had 17 complaints lodged with the Network for a baseline mean patient complaint measure of 1.9. During the 2008 study period (May 2008–April 2009), the number of complaints to the Network dropped to nine (mean = 1). This rate failed to meet the original project goal of a 50% reduction (≤0.9). Despite the shortfall, and recognizing the barriers to pursuing the project in its orginal format, the decline in complaints was viewed positively. Figure 1 illustrates the change in rate of complaints to the Network during the project year among the nine participating facilities.

**Figure 1.** Change in the Median Rate of Complaints Between Base Year 2007 and the Project Year



Facilities evaluated their participation in the project favorably (87.5% response rate, see Table 3). Interventions rated as most effective were related to increasing skills in root cause analysis and developing and implementing a plan of change. Facilities were least confident in graphing quality measures and understanding the QI process, and this was observed by the Network. Most of the participating facilities had data tracking systems in place by the first reporting month. However, the ability to clearly articulate the goals and measures of the interventions took several reporting periods to develop.

## DISCUSSION

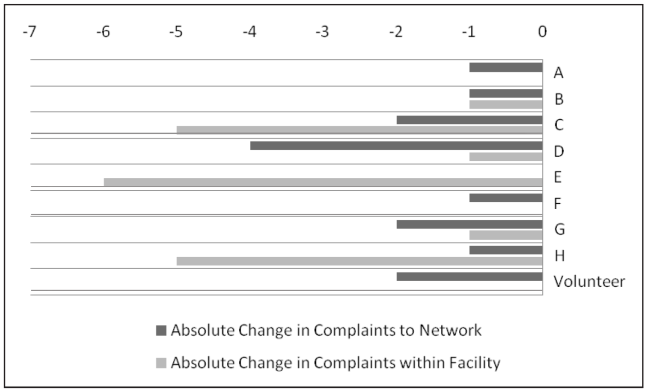
With the implementation of the new Medicare Conditions for Coverage looming on top of an already stressed system (staffing shortage, budget constraints, paper work requirements, etc.), the targeted facilities expressed discontent with being required to participate in this project. It was viewed as burdensome and punitive. There was also a knowledge deficit with regard to QI application among all the facilities, which necessitated ongoing teaching, an unanticipated time-resource commitment for both the Network and participants. Additionally, participants struggled with the monthly reporting template, which was based on the PDSA cycle and utilized QI language (e.g., baseline data and aim statement). Narrative instruction was included with each section and feedback on monthly reports was provided to assist with completion.

It is interesting to note the comparison between the number of complaints received by the Network and those observed within the facilities. For example, Units E and G both had the highest percentage of complaints to the Network among the participating facilities (23.1% each). Although Unit E had the greatest numerical decrease in complaints within its own project, there was no change in complaints received by the Network. Unit G, by comparison, reduced by half both the complaints within its own project and those received by the Network (see Figure 2). The difference may indicate that Unit E had not mastered

**Table 3.** *Project End Facility Evaluation*

| **As a result of participating in this project …** | **Strongly Agree** | | **Neutral** | | **Strongly Disagree** |
|---|---|---|---|---|---|
| | 5 | 4 | 3 | 2 | 1 |
| I have a greater understanding of conflict in my facility. | | 4.42 | | | |
| I am better able to identify the root causes of conflict in my facility. | 4.57 | | | | |
| I have increased my skill in developing a plan of change. | | 4.43 | | | |
| I have increased my skill in implementing a plan of change. | | 4.43 | | | |
| I understand how to define a quality measure. | | 4.00 | | | |
| I have increased my skill in graphing quality measures over time. | | 3.86 | | | |
| I have a better understanding of the Quality Assessment and Performance Improvement (QAPI) process. | | 4.00 | | | |
| I obtained resources throughout the project from the Network that were helpful. | | 4.42 | | | |

**Figure 2.** Change in Complaints



*None of the units had an increase in complaints either to the Network or internally. All but one experienced a decrease in rate of complaints to the Network.*

data collection or was under-reporting, or that the area targeted for improvement was not sensitive enough to affect the concerns that were reaching the Network level.

Despite the barriers, participants demonstrated improvement in their understanding and application of the QI process overall. Eight out of nine units had a decrease in the number of complaints received by the Network, and six made significant progress with their own internal goals. The majority of the participants reported that project participation was helpful in preparing for the demands of the newly released ESRD Conditions for Coverage and gained confidence in their ability to recognize and impact issues within their facility.

## LIMITATIONS

The project's main limitations were self-reporting and threats to internal and external validity due to use of a quasi-experimental design that lacked both a comparison group and random selection of facilities for inclusion in the treatment group. With regard to the latter, the study involved a group of facilities that were complaint outliers. Consequently, the results may not be generalizable to all dialysis facilities. Without a comparison group, it cannot be assumed that complaints would not have decreased without the intervention.

No exclusions were given to repeat complainants. There was also no distinction made between repeat complainants within the same year or throughout the noted years. Had these exclusions occurred, it is likely that two of the facilities would not have been targeted for participation. Future endeavors of this kind may wish to establish more rigid criteria for inclusion of such complaints.

Facilities were expected to select their own goals and were trusted to report accurately and completely their activities and findings. The project's design was chosen to capitalize on the QAPI requirements of the new Medicare Conditions for Coverage. It empowered facilities with the ability to apply the principles to their own real and unique issues of conflict and patient satisfaction.

Because conflict resolution is a learned skill, the observable gains made by these participants may weaken if facilities do not maintain the processes that they have put in place. Clearly, the new regulations expect that facilities will establish these practices and implement QI processes appropriately when indicated.

The Network incorrectly assumed that all facility administrators had the appropriate training and background knowledge to conduct and report on QI. This error required an unanticipated demand of resources for necessary training, which delayed the initiation and progression of the project. Social workers are in a position to take a leadership role on QI within their units. As part of the required curriculum, the Master's-prepared social worker has demonstrated research skills, which include developing goals, establishing measures and reporting findings at a level acceptable for publication.

Future endeavors of this kind would benefit from spending more time initially in one-on-one discussions with participants to determine their knowledge of QI, examine the systems already in place in each facility that can be expanded or improved and assist in overall preparation for the facility's participation. Preparation may further include determining additional training or education needs and planning for resources to address those needs. Involvement of facilities' corporate resources might be solicited for additional tutoring when facilities are determined to have limited comprehension of QI application.

## CONCLUSION

The project did not achieve its goal, but did make important improvements. All but one facility experienced a decrease in complaints to the Network. Despite the variation in competency, each facility improved its QI skill level and established complaint tracking logs, which most did not have previously. This experience underscored the Network's concern that facilities did not have adequate QI processes in place. The Network underestimated the QI knowledge base of facility administrators enrolled in this project, and the project was not feasible without this knowledge and the ability to apply it. Consequently, the project's focus had to change with an unanticipated cost in time resources for ongoing training.

Facilities perceived benefit from project participation. Interventions rated as most effective were related to increasing skills in root cause analysis and developing and implementing a plan of change. Facilities reported being least confident in graphing quality measures and understanding the QI process, but demonstrated improvement in application. Participants also viewed the materials and resources that the Network provided throughout the project as helpful.

QAPI is a requirement of the ESRD regulations and must focus on several indicators, including patient satisfaction and complaints (ref: §494.110(a)(2)(viii)), and facilities must address identified deficiencies. Determining how to affect change requires facilities to actively identify issues and look closely for root causes to better select interventions. Repeat patient complainants should not be summarily discounted without full evaluation of legitimacy. Dialysis organizations would benefit from assessing facility QI knowledge and skill sets, and providing more QI training and guidance where indicated. With processes in place to track and impact undesirable trends, satisfaction among patients and staff is increased.

## ACKNOWLEDGEMENT

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## APPENDIX A

*QAPI Training Agenda*

**QAPI processes**

- Developing an "aim statement"
- Utilizing rapid cycle improvement
- Determining root causes
- Understanding measures

**Tools (found in the DPC toolkit)**

- Conflict log
- Taxonomy
- Glossary
- Interactive CD-ROM

**Techniques**

- Annotated run chart

**Resources and references**

- DPC toolkit (provided to each of the participating units)
- **www.wendyleebov.com**
- **www.fosterseminars.com**
- Mid-Atlantic Renal Coalition staff in-service modules (**http://esrdnet5.org/inservice.asp**)
- PDSA worksheet (**http://www.ihi.org/IHI/Topics/Improvement/ImprovementMethods/Tools/Plan-Do-Study-Act+%28PDSA%29+Worksheet.htm**)
- Conflict management change concepts

## APPENDIX B

### *Conflict Management Change Concepts*

Change Ideas: Recommended change strategies that can be employed for decreasing conflict in the dialysis unit.

**Routine QAPI review of patient complaints/incidents**

- Assemble multidisciplinary team.
- Conduct root cause analysis (inclusion of staff in this exercise will increase ownership of process).
- Designate staff member in dialysis facility responsible for recording reported complaints and incidents of conflict (facility administrator if feasible, but can be any renal care professional). Incorporate into facility-based QAPI process.
- Obtain retrospective data and conduct future collection, reporting and review.
- Track/trend complaints (DPC QI tools are recommended).
- When indicated by data, improvement activities will be initiated.
- Facilities adopt standard practice for staff reporting of complaints/incidents.

**Routine staff training**

- Designate staff member(s) in dialysis facility responsible for providing staff training in conflict management (ideally the facility administrator or clinical educator, but can be any renal care professional in authority and with favorable presentation skills and knowledge base). Incorporate into facility-based staff training process.
- Staff utilizes DPC taxonomy and glossary.
- Staff receives training in areas such as customer service, communication skills, professionalism/boundaries and patient-centered care.
- Staff receives training in conflict management and conflict resolution skills with utilization of the DPC C-O-N-F-L-I-C-T model.

**Enhance patient–provider relationships**

- Multidisciplinary team reviews and identifies facility culture related to areas such as patient autonomy, patient centeredness, conflict and facility policies (zero tolerance, grievance policy, treatment rescheduling, patient comforts, care planning and responses to patient non-adherence).
- Staff receives education in areas such as cultural competency and triggers/escalation of conflict.
- Data feedback is shared with all staff as an educational tool to facilitate buy-in and ownership.
- Staff is provided debriefing following all unusual conflict incidents to review what happened, what was done well, what could have been done differently/better and what is to be done going forward.
- Patients receive education in areas such as cultural competency, changes in unit policy and procedure and the unit grievance process.
- Patients are encouraged to participate in care planning.
- Patients are encouraged to participate in self-care.

# CNSW Research Grants Program

National Kidney Foundation®
Council of Nephrology Social Workers

## PURPOSE

In keeping with the overall goals of the National Kidney Foundation (NKF) and its Council of Nephrology Social Workers (CNSW), the purpose of the CNSW Research Grant Program is to further knowledge of psychosocial factors in kidney failure and to enhance clinical social work intervention with dialysis and transplant patients/families.

## AREAS OF INTEREST

- Research on psychosocial factors in kidney failure
- Clinical practice research projects focusing on social work assessment and treatment strategies with patient/families or staff
- Educational programs to enhance patient/family understanding of kidney failure treatment and its psychosocial implications
- Pilot or demonstration projects which have broad applicability to nephrology social work services and/or nephrology social workers

## ELIGIBILITY

Grant applications must meet the following eligibility requirements:

- Regular membership in CNSW
- Minimum of two years nephrology social work experience (CMS Guidelines)
- Approval of the department head or facility director of the organization within which the research is to be conducted
- Residence in the United States or its territories
- Applicant must meet the definition of a “qualified social worker” as stated in the Conditions for Coverage

Preference will be given to applicants who:

- Have ACSW accreditation or are licensed by their state

Awards will be announced in March. The Review Committee reserves the right to award grants or to decline funding without stating its reasons.

## GRANT REQUIREMENTS

Each grant recipient is responsible for:

- Conducting the project as set forth in the proposal and consistent with accepted, systematic research methods
- Obtaining appropriate human studies clearance within the dialysis/transplant facility and maintaining data in a confidential manner
- Completing the project within the specified time frame
- Providing financial reports as required by the National Kidney Foundation
- Acknowledging NKF/CNSW grant assistance on all publications arising out of the work done during the duration of the grant
- Submitting three interim progress reports and other requested reports, preparing a final report of the work accomplished within 60 days of the end of the grant year, and presenting a paper at the NKF Spring Clinical Meetings describing the research, results and implications for practice
- Submitting a manuscript based on the results to *The Journal of Nephrology Social Work* (and with the committee’s approval, another related journal)

## FUNDING

- CNSW annually requests grant monies from NKF.
- One or more grants may be awarded. Applicants submitting to more than one granting agency will be awarded the difference between the amount awarded by the other agency and the amount applied for from CNSW.
- CNSW grants assist in defraying the cost of research and projects. They are not intended to cover the entire cost of the research (i.e., office space, basic supplies, services, overhead, administration fees).
- Funds may not be used for the purchase of equipment.
- Budgets must allocate $750.00 for airfare and one night’s accommodation to enable grantees to present their research at the NKF Spring Clinical Meetings. This amount will be withheld until the first draft of the manuscript is received by the *Journal of Nephrology Social Work* co-editors and the awardee has presented findings at the next NKF Spring Clinical Meetings.
- Funding for CNSW research grants runs from July 1 of the year of approval through June 30 of the following year.

# CNSW Research Grants Program *(cont'd)*

## HOW TO APPLY

If you are interested in preparing a proposal, please submit a letter of intent to the CNSW Research Grant Program, c/o the National Kidney Foundation by **October 15**. Your letter of intent is not part of your actual application, but rather a device to assist you and the grants coordinator in identifying your research objectives and goal. The letter of intent must include the following:

1. Name of the person and organization submitting the proposal
2. Address
3. Telephone number
4. Name of the principal investigator and his or her CNSW membership number
5. Short title of the project
6. Approximate cost
7. Brief abstract under 250 words, which includes:
   a. A description of the project goal
   b. How it relates to the purpose of CNSW research

Upon receipt and acceptance of your letter of intent, NKF-CNSW will send you a grant application packet.

## CONSULTATION COMMITTEE

CNSW has volunteer consultants available to provide recommendations and prior review of your proposal. For more information, please contact your CNSW Region Representative or the CNSW Chair-Elect.

*Review Schedule*

| | |
|---|---|
| October 15 | Letter of intent due |
| December 1 | Grant Proposal due |
| January – February | Council Research Grants Committee Review |
| March | Awards Announced |
| July 1 | Approved projects begin operation and continue until June 30th of the following year. |

The Council of Nephrology Social Workers (CNSW) is a professional organization established by nephrology social workers in 1973. CNSW is one of four Professional Councils of the National Kidney Foundation (NKF). The functional structure of CNSW includes an Executive Committee with regional representation, standing and ad hoc committees, and local chapters.

For more information contact:

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**www.kidney.org/professionals/CNSW**

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