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.

The Council of Nephrology Social Workers of the National Kidney Foundation

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- Professional Roles
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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 research and interest in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. The *Journal* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

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

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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.

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Order of the Manuscript Sections

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

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

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

Reference Examples

Journal Article, Two Authors

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

Journal Article, Three to Six Authors

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

Journal Article, More Than Six Authors

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

Journal Article in Press

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

Complete Book, Edited

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

Chapter of an Edited Book

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

Article from a Journal Supplement

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

Abstract

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

Editorial

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

ACCEPTANCE PROCESS

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

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Changes in Dialysis Social Workers' Caseloads, Job Tasks, and Hourly Wages Since the Implementation of the 2008 Conditions for Coverage

Joseph R. Merighi, PhD, Associate Professor, Boston University School of Social Work, Boston, MA

This study examined the job-related experiences of dialysis social workers since the implementation of the 2008 Centers for Medicare and Medicaid Services Conditions for Coverage for End-Stage Renal Disease Facilities. Data were obtained from 231 part-time and 1,091 full-time dialysis social workers (N = 1,322) who responded to an online survey conducted in 2010 by the National Kidney Foundation Council of Nephrology Social Workers (NKF CNSW). Findings indicated that 41.2% of part-time and 50.1% of full-time social workers reported an increase in their patient caseloads. Similarly, 80.2% of part-time and 85.9% of full-time respondents reported an increase in job tasks, and 70.4% of the part-time and 76.6% of the full-time workers reported that they had insufficient time to provide psychosocial services to patients. Approximately one-half (49.2%) of full-time social workers indicated being somewhat or very dissatisfied with their caseloads, and more than one-half of part-time (50.4%) and full-time (52.8%) social workers indicated being somewhat or very dissatisfied with their job tasks. No differences in hourly wage changes were found between part- and full-time respondents since the implementation of the 2008 Conditions for Coverage. Implications for nephrology social work practice and research are discussed.

INTRODUCTION

Nephrology social workers are central to the provision of biopsychosocial services that are mandated by the Centers for Medicare and Medicaid Services Conditions for Coverage (CfC) for End-Stage Renal Disease Facilities (Federal Register, 2008). The CfC are federal regulations that ensure the health and safety of people who require dialysis or a kidney transplant as life-saving interventions. As patients with end-stage renal disease (ESRD) begin their dialysis care, they often face difficulties such as managing intensive treatment regimens and coping with the social, vocational, and mental health challenges that result from being on a renal replacement therapy. Social workers in dialysis facilities are specifically trained to provide practical and psychological support to help patients manage the treatment process (Browne, 2012). Some of the primary interventions offered by social workers include patient and family education, supportive counseling, crisis intervention, provision of information and community referrals, interdisciplinary care planning and collaboration, and patient advocacy (Browne, 2012; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2001; McKinley & Callahan, 1998; McKinley, Schrag, & Dobrof, 2000; Merighi & Ehlebracht, 2004a, 2004b, 2004c; Russo, 2002; Wolfe, 2011). These interventions help renal patients to cope with the physical and mental health consequences that are often associated with a diagnosis of ESRD (Browne, 2012; Cukor, Peterson, Cohen, & Kimmel, 2006), and can help promote treatment adherence and self-management (Browne & Merighi, 2010; Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). Studies have documented the positive effect that social work interventions such as clinical counseling and education have on ESRD patients' psychological well-being and quality of life (Beder, 1999; Dobrof et al., 2001; McCool et al., 2011; Sledge et al., 2011).

Health care environments in the United States are increasingly driven by consumer demands, corporate streamlining, cost containment, and state and federal regulations. The cumulative burden of these workplace factors, in addition to increasing caseload size and patient acuity, can affect health care providers' job satisfaction, and consequently, patient outcomes and quality of life. Research on overall job satisfaction of social workers in health care settings has shown that the majority of these professionals are either satisfied or very satisfied with their work (Gellis, 2001; Merighi & Ehlebracht, 2004c; Siefert, Jayarante, & Chess 1991). However, a study on the effect of organizational reengineering on job satisfaction indicated that hospital-based social workers reported higher levels of dissatisfaction as a result of organizational changes that were implemented to reduce costs and streamline service delivery systems (Neuman, 2003). Although this research provides information about the job satisfaction of health care social workers in general, relatively little is known about *nephrology* social workers' job satisfaction, especially since the implementation of the 2008 CfC.

To assist patients with end-stage renal disease, nephrology social workers must have adequate time and resources to complete required documentation and provide their patients with psychosocial support services as mandated in the 2008 CfC. Previous research, which was conducted prior to the implementation of the 2008 CfC, has documented the high prevalence of nonclinical tasks that are required of dialysis social workers (Merighi & Collins, 2011; Merighi & Ehlebracht, 2002, 2004a, 2004b, 2004c). From this research, we discovered that 94.9% of the dialysis social workers surveyed indicated that counseling was an appropriate use of their social work training. Despite the importance of providing counseling to patients and their families, only one third of these social workers (33.7%) reported that they had ample time to provide clinical social work services (Merighi & Ehlebracht, 2004c).

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Counseling and psychosocial assessment were maintained as key social work activities in the 2008 Conditions for Coverage. However, the CfC final rule now requires a "psychosocial status" component in a patient's plan of care. This component outlines how professional social work services are provided to ESRD patients and how standard mental and physical health assessments, e.g., the Kidney Disease Quality of Life-36 (KDQOL-36) survey, are used to evaluate their functioning (Federal Register, 2008). A plan of care needs to be developed within 30 days of a patient's admission to a dialysis facility (or within 13 dialysis sessions) and updated regularly in accord with CfC guidelines. In addition, social workers are expected to participate in an interdisciplinary team, which is comprised of at least an ESRD physician, registered nurse, social worker, dietitian, and patient (if feasible). This team is charged with preparing a written, individualized, and comprehensive plan of care that outlines the specific mental and physical health needs of the patient, as determined by an interdisciplinary assessment. A social worker's involvement in an interdisciplinary team is not a new role in an ESRD setting; however, the implementation of the 2008 CfC has markedly increased the social worker's level of responsibility on this team (e.g., having to administer the KDQOL-36). It is unclear if fulfilling all CfC-mandated tasks leaves nephrology social workers with sufficient time and opportunities for essential clinical work with patients and their support systems.

High caseloads can hinder dialysis social workers' ability to provide adequate clinical services to their patients (Merighi & Ehlebracht, 2002). Nephrology social workers' caseloads in dialysis units often exceed the National Kidney Foundation Council of Nephrology Social Workers (NKF CNSW) recommendation of 75 patients per full-time social worker (CNSW, 1998, Merighi, Browne, & Bruder, 2010; Merighi & Ehlebracht, 2004a). Although study findings have shown that large patient caseloads are associated with decreased patient satisfaction and less patient access to rehabilitation services (Callahan, Moncrief, Wittman, & Maceda, 1998), dialysis social workers continue to be responsible for caseloads that exceed the CNSW recommendation. Further, as the population of patients on dialysis comes to include a greater proportion of medically and psychosocially complex cases, social workers will be further challenged to provide essential services to their patients in accordance with the 2008 CfC. Between 2007 and 2010, the mean caseload size for outpatient dialysis social workers in the United States increased 8.2% for part-time employees (20–31 hours per week) and 7.1% for full-time employees (32–40 hours per week) (Merighi et al., 2010). These increases in patient caseloads, in addition to changes in job responsibilities and expectations, highlight the need to examine the experiences of dialysis social workers since the implementation of the 2008 CfC.

Study Aim

The aim of this study is to examine the influence of the 2008 Centers for Medicare and Medicaid Services Conditions for Coverage for End-Stage Renal Disease Facilities on part-time and full-time dialysis social workers' caseloads, job tasks, and hourly wages.

METHOD

Study Design

A cross-sectional survey research design was used to assess caseload, hourly wage, and other job-specific issues of nephrology social workers employed in the United States. For the purpose of this article, only data from respondents employed in dialysis facilities were analyzed.

Respondents

More than 88% ($N = 1{,}322$) of the 1,495 social workers who responded to the CNSW online survey were employed in a dialysis facility either part-time (20–31 hours per week, $n = 231$) or full-time (32 or more hours per week, $n = 1{,}091$). The majority of survey respondents (99.2%) had a Master of Social Work degree, were women (91.1%), licensed in their state (83.7%), employed full-time (82.5%), and worked for a for-profit dialysis facility (79.9%). The sample was 85.7% White, 9.6% Black/African American, 2.9% Asian American/Pacific Islander, 1.0% American Indian/Native American, and 0.8% multiracial. Less than one-tenth of the social workers (7%) identified as Hispanic/Latino. The respondents' mean age was 46.9 (standard deviation [SD] = 11.6) years and their mean length of nephrology social work practice experience was 8.8 (SD = 7.3) years. See Table 1 for a demographic comparison between the part-time and full-time respondents and the total sample. When comparing the part-time and full-time social workers, part-time respondents were older [$t(1{,}278) = 4.4$, $p < .001$] and had more renal social work experience, [$t(1{,}312) = 3.0$, $p < .01$]. In addition, part-time and full-time social workers differed in terms of their geographic location as measured by National Kidney Foundation (NKF) region [$\chi^2(4, N = 1{,}321) = 11.75$, $p < .05$]. No other differences between part- and full-time respondents were found. This study received Institutional Review Board approval from Boston University and was conducted in accordance with the guidelines on evaluation and research described in the Code of Ethics of the National Association of Social Workers (NASW, 2008).

Measure

The 2010 NKF CNSW Salary and Caseload Survey was comprised of 130 open- and close-ended questions that examined social work respondents in the following domains: demographic characteristics, work environment issues, caseloads, hourly wages, professional tasks, job satisfaction, emotional exhaustion, workload demands, and negative affectivity. Survey items were developed by several

Table 1. *Dialysis Social Workers Sample Demographics*

	Total sample ***N* = 1,322** *M* (*SD*)	**Full-time** ***n* = 1,091** *M* (*SD*)	**Part-time** ***n* = 231** *M* (*SD*)
Age (years)	46.9 (11.6)	46.3 (11.7)	49.9 (10.9)***
Years with current employer	7.1 (6.5)	6.9 (6.4)	7.8 (7.2)
Years worked in renal social work	8.8 (7.3)	8.5 (7.1)	10.1 (7.8)**
	%	%	%
Gender			
Female	91.1	90.4	94.7
Male	8.8	9.5	5.3
Transgender	0.1	0.1	—
Race			
African American/Black	9.6	10.5	5.5
American Indian/Native American	1.0	1.0	0.9
Asian American/Pacific Islander	2.9	3.1	1.8
White	85.7	84.5	91.3
2 or more races	0.8	0.9	0.5
Hispanic ethnicity (Yes)	7.0	7.2	6.1
Primary employer type			
For-profit dialysis facility	79.9	80.7	76.1
For-profit hospital	1.3	1.1	2.2
Non-profit dialysis facility	9.4	8.8	12.1
Non-profit/public hospital	9.0	9.1	8.7
Other	0.4	0.3	0.9
Licensed in state (Yes)	83.7	82.9	87.3
MSW degree (Yes)	99.2	99.2	99.6
NKF Region			
1	19.8	19.1	22.9*
2	24.4	25.2	20.4
3	25.2	23.8	32.0
4	11.8	12.3	9.5
5	18.8	19.6	15.2

Note. U.S. states that comprise the five NKF regions are defined as follows: 1 (CT, DE, ME, MD, MA, NH, NJ, NY, PA, RI, VT); 2 (AL, DC, FL, GA, KY, MS, NC, SC, TN, VA, WV); 3 (IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, SD, WI); 4 (AR, LA, NM, OK, TX); and 5 (AK, AZ, CA, CO, HI, ID, MT, NV, OR, UT, WA, WY). Significant differences were found between full- and part-time respondents for NKF region (**p* < .05), years worked in renal social work (***p* < .01), and age (****p* < .001).

representatives of the CNSW Executive Committee in collaboration with the author. For the purpose of this article, only demographic, work environment, caseload, hourly wage, professional tasks, and job satisfaction variables were analyzed. The majority of these domains were measured using forced-choice questions. For example, "Overall, how satisfied are you with your job tasks: *very dissatisfied*, *somewhat dissatisfied*, *neither satisfied nor dissatisfied*, *somewhat satisfied*, or *very satisfied*." Only two variables (caseload and hourly wage) required a unique response from respondents. For example, "How much do you get paid on an hourly basis? If you are a salaried employee who works full-time (40 hrs/wk), please take your yearly salary and divide it by 2080. [Example: $60,000 divided by 2080 = $28.85.]"

Data Collection Procedure

The survey instrument was administered online by the NKF between March 21 and June 21, 2010. The NKF distributed announcements about the survey to its CNSW members via a membership email LISTSERV, which reaches the majority of CNSW members. The announcements included information about the study aims, instructions on how to access the survey, and requests to distribute the announcement to other nephrology social workers (including non-CNSW members). Prospective respondents were informed of the confidential and voluntary nature of the survey and no incentives were offered for participation. The survey took approximately 25 minutes to complete. All data were initially sent to NKF and housed on their secure server prior to their release for statistical analysis. Once the data were de-identified by NKF staff (i.e., by removing email addresses and other information that could potentially reveal the identity of an individual respondent), the author received them in an Excel spreadsheet. All the data sent to the author are stored on a secure network at Boston University.

Data Analysis

Chi-square tests and independent samples t-tests were used to assess all descriptive variables for differences between part- and full-time respondents. In addition, chi-square tests were used to analyze all categorical variables (e.g., job tasks) for differences between part- and full-time respondents. Yates continuity correction was used for 2 x 2 contingency tables when performing chi-square analyses. One-way analysis of variance with Bonferroni post hoc comparisons were used to test for differences in means for two continuous variables (i.e., caseload and hourly wage). To reduce the risk of Type I errors, adjusted p-values were computed to take into account multiple comparisons. Individual sample sizes are reported to identify where data were missing at random. Statistical analyses were performed using SPSS 10.0 (Chicago, IL).

RESULTS

Changes in Caseloads, Job Tasks, and Hourly Wages

Since the implementation of the 2008 CfC, 41.2% of part-time and 50.1% of full-time dialysis social workers reported increases in their patient caseloads, with a greater proportion of full-time respondents reporting an increase in caseload size [$\chi^2(2, N = 1{,}290) = 6.12, p < .05$]. See Table 2. Bonferroni post hoc tests were performed to test, within group differences, mean caseload between respondents who indicated "decreased," "stayed the same," or "increased" as a result of the 2008 CfC. Significant main effects were found for both part-time [$F(2, 208) = 7.1, p < .001$] and full-time respondents [$F(2, 1{,}010) = 38.8, p < .001$], which justified the use of post hoc analyses. For part-time respondents, the mean caseload for those who reported that it increased (87.1) was significantly higher than those respondents who reported that it stayed the same (73.2; $p < .001$). For full-time respondents, differences in mean caseload were found for all possible group pairings. The highest reported caseload was found for those full-time respondents who indicated an increase since the implementation of the 2008 CfC (130.9), compared to those who reported that it stayed the same (111.9) or decreased (95.7). See Table 3.

With regard to job tasks, 80.2% of part-time and 85.9% of full-time respondents reported an increase in job tasks, with a greater proportion of full-time workers reporting more tasks being performed since the implementation of the CfC [$\chi^2(2, N = 1{,}286) = 10.59, p < .01$]. Differences in the proportion of responses between part- and full-time respondents were also found for authorized work hours [$\chi^2(2, N = 1{,}280) = 24.92, p < .001$] and non-paid hours [$\chi^2(2, N = 1{,}272) = 18.53, p < .001$]. See Table 2.

No differences were found in the proportion of part- and full-time social workers who reported changes in their hourly wages. Significant main effects were found for only full-time respondents [$F(2, 1{,}029) = 9.2, p < .001$], which supported within group comparisons using a Bonferroni post hoc test. Specifically, a significant difference in mean hourly wage emerged between full-time respondents who reported that it stayed the same ($26.90) and those who indicated that it increased ($28.55). See Table 3.

Level of Satisfaction with Job-related Factors

In addition to assessing the influence of the 2008 CfC in key job domains, respondents were asked to report their current level of satisfaction with the following: caseload, hourly wage, benefits, job tasks, and work environment. With regard to caseload, 37.1% of part-time and 49.2% of full-time dialysis social workers reported being either somewhat or very dissatisfied, with a greater proportion of full-time respondents reporting dissatisfaction [$\chi^2(4, N = 1{,}312) = 17.58, p < .001$. See Table 4. Bonferroni post hoc tests were performed to test for within group differences in mean caseload between respondents who indicated that

Table 2. *Changes Since the Implementation of the 2008 Medicare and Medicaid Conditions for Coverage for Full- and Part-time Dialysis Social Workers*

	Decreased (%)	**Stayed about the same (%)**	**Increased (%)**
Caseload*			
Full-time (*n* = 1,062)	3.1	46.8	50.1
Part-time (*n* = 228)	3.1	55.7	41.2
Hourly wage			
Full-time (*n* = 1,058)	4.3	79.9	15.8
Part-time (*n* = 228)	4.4	79.8	15.8
Job tasks**			
Full-time (*n* = 1,059)	0.3	13.8	85.9
Part-time (*n* = 227)	1.7	18.1	80.2
Authorized work hours***			
Full-time (*n* = 1,054)	7.5	85.1	7.4
Part-time (*n* = 226)	16.4	71.7	11.9
Non-paid hours***			
Full-time (*n* = 1,052)	2.6	58.3	39.1
Part-time (*n* = 220)	6.8	65.9	27.3

*$p < .05$. **$p < .01$. ***$p < .001$.

Table 3. *Caseload and Hourly Wage by Perceived Change Since the Implementation of the 2008 Medicare and Medicaid Conditions for Coverage for Full- and Part-Time Dialysis Social Workers*

	Decreased M (SD)	Stayed about the same M (SD)	Increased M (SD)
Caseload			
Full-time (n = 1,013)	95.7 (24.5)^a	111.9 (28.5)^b	130.9 (46.5)^{ab}
Part-time (n = 211)	72.4 (27.2)	73.2 (22.6)^a	87.1 (30.7)^a
Hourly wage (in U.S. Dollars)			
Full-time (n = 1,032)	28.04 (3.69)	26.90 (4.56)^a	28.55 (5.69)^a
Part-time (n = 222)	26.21 (4.17)	28.10 (4.70)	29.20 (5.86)

Note. Pairs of superscripted letters within an employment category (full-time or part-time) represent significantly different pairs of means. Bonferroni post hoc test, $p < .001$.

they were either “somewhat or very dissatisfied,” “neutral,” or “somewhat or very satisfied.” Significant main effects were found for both part-time [$F(2, 209) = 12.5$, $p < .001$] and full-time respondents [$F(2, 1{,}026) = 62.6$, $p < .001$], which justified the use of post hoc analyses. For part-time respondents, the mean caseload for those who reported being somewhat or very dissatisfied (88.5) was significantly higher than those respondents who reported being somewhat or very satisfied (68.6; $p < .001$). For full-time respondents, significant differences in mean caseload were found for all possible group pairings. The highest reported caseload was found for those respondents who indicated being somewhat or very dissatisfied (133.4), compared to those who indicated being neutral (118.2) or somewhat or very satisfied (103.9). See Table 5. With regard to job tasks, slightly more than half of the part-time (50.4%) and full-time (52.8%) respondents reported being somewhat or very dissatisfied, with a greater proportion of full-time workers reporting dissatisfaction [$\chi^2(4, N = 1{,}311) = 10.22$, $p < .05$].

No significant differences in satisfaction with hourly wage were found between part- and full-time respondents. Significant main effects were found for only full-time respondents [$F(2, 1{,}050) = 20.2$, $p < .001$], which supported within group comparisons using a post hoc test. Specifically, a significant difference in mean hourly wage emerged between full-time respondents who reported being somewhat or very dissatisfied ($26.13) and those who indicated being somewhat or very satisfied ($28.08). See Table 5.

Responsibility for Job Tasks

Respondents rated their level of responsibility for 22 job tasks in dialysis facilities by indicating “not responsible,” “partially responsible,” or “solely responsible.” The majority (> 50%) of part-time and full-time social workers indicated that they were “solely responsible” for the following six tasks: 1) completing the KDQOL-36 survey; 2) individual counseling; 3) family counseling; 4) assisting outgoing transient patients; 5) coordinating transportation; and 6) administering patient satisfaction surveys. No statistically significant differences were found between part- and full-time social workers. See Table 6.

Employer-provided Benefits

Social workers in this study indicated the availability of employer-provided benefits by responding “yes,” “no,” or “don’t know” to a list of 19 benefit categories. The majority of part-time and full-time social workers (> 50%) indicated that their employers provided the following seven benefits: 1) health insurance; 2) vacation/sick pay; 3) 401K/403B retirement plans; 4) gas/mileage reimbursement; 5) paid time off to attend conferences; 6) holiday pay; and 7) merit increases. Significant differences between part-time and full-time respondents were found for two benefit categories: health insurance [$\chi^2(2, N = 1{,}303) = 48.35$, $p < .001$] and gas/mileage reimbursement [$\chi^2(2, N = 1{,}305) = 14.62$, $p < .001$]. See Table 7.

Supplemental Analyses

Two supplemental analyses were performed to test for differences between part- and full-time respondents with regard to the following questions: 1) Do you have enough

Table 4. *Level of Satisfaction for Full- and Part-Time Dialysis Social Workers*

	Very dissatisfied (%)	Somewhat dissatisfied (%)	Neither satisfied nor dissatisfied (%)	Somewhat satisfied (%)	Very satisfied (%)
Caseload***					
Full-time (*n* = 1,083)	21.0	28.2	16.8	24.0	10.0
Part-time (*n* = 229)	14.8	22.3	23.1	23.1	16.7
Hourly wage					
Full-time (*n* = 1,084)	10.1	29.4	11.7	37.5	11.3
Part-time (*n* = 230)	8.7	24.8	11.3	42.2	13.0
Benefits					
Full-time (*n* = 1,084)	5.0	20.0	13.5	42.5	19.0
Part-time (*n* = 229)	6.6	18.8	18.3	40.6	15.7
Job tasks*					
Full-time (*n* = 1,081)	15.6	37.2	14.5	28.3	4.4
Part-time (*n* = 230)	15.2	35.2	17.9	23.0	8.7
Work environment					
Full-time (*n* = 1,082)	9.1	17.9	15.9	35.5	21.6
Part-time (*n* = 228)	7.0	19.7	13.7	34.2	25.4

*$p < .05$. ***$p < .001$.

Table 5. *Caseload and Hourly Wage by Level of Satisfaction for Full- and Part-Time Dialysis Social Workers*

	Very or somewhat dissatisfied *M (SD)*	**Neither satisfied nor dissatisfied** *M (SD)*	**Very or somewhat satisfied** *M (SD)*
Caseload			
Full-time (*n* = 1,029)	133.4 (43.1)^{ab}	118.2 (27.3)^{ac}	103.9 (34.0)^{bc}
Part-time (*n* = 212)	88.5 (27.1)^{a}	81.2 (28.6)	68.6 (22.3)^{a}
Hourly wage			
Full-time (*n* = 1,053)	26.13 (4.36)^{a}	27.01 (4.59)	28.08 (4.96)^{a}
Part-time (*n* = 224)	27.28 (4.94)	27.69 (4.84)	28.79 (4.83)

Note. Pairs of superscripted letters within an employment category (full-time or part-time) represent significantly different pairs of means. Bonferroni post hoc test, $p < .001$.

Table 6. *Level of Responsibility for Job Tasks by Full- and Part-Time Dialysis Social Workers*

	Work status	***n***	**Not responsible (%)**	**Partially responsible (%)**	**Solely responsible (%)**
KDQOL-36	FT	1,087	1.6	3.9	94.5
	PT	230	0.4	3.9	95.7
Individual counseling	FT	1,081	4.9	21.6	73.5
	PT	225	4.9	25.3	69.8
Family counseling	FT	1,077	10.1	25.2	64.7
	PT	228	11.8	26.3	61.9
Assisting outgoing transient patients	FT	1,083	11.0	28.3	60.7
	PT	228	8.3	30.3	61.4
Transportation	FT	1,082	3.4	37.7	58.9
	PT	230	2.6	41.7	55.7
Patient satisfaction survey	FT	1,077	20.1	28.9	51.0
	PT	229	20.5	24.0	55.5
Behavioral contracts	FT	1,073	3.6	51.5	44.9
	PT	230	4.8	56.5	38.7
CMS Form 2728	FT	1,075	32.4	24.7	42.9
	PT	228	31.6	23.7	44.7

(continued)

Table 6. *Level of Responsibility for Job Tasks by Full- and Part-Time Dialysis Social Workers (Continued)*

	Work status	*n*	Not responsible (%)	Partially responsible (%)	Solely responsible (%)
Medicaid paperwork	FT	1,078	22.4	37.7	39.9
	PT	229	21.8	35.8	42.4
Support groups	FT	1,067	44.1	22.3	33.6
	PT	224	46.4	21.0	32.6
Incoming transient patients	FT	1,079	38.6	35.6	25.8
	PT	226	39.8	36.7	23.5
Educational groups	FT	1,071	37.3	42.1	20.6
	PT	227	42.3	37.9	19.8
Scheduling care plan meetings	FT	1,085	41.6	44.6	13.8
	PT	226	50.0	36.7	13.3
Patient social activities	FT	1,067	32.1	54.4	13.5
	PT	227	36.6	48.0	15.4
Staff counseling/support	FT	1,072	17.5	69.4	13.1
	PT	227	17.2	73.1	9.7
Insurance verification	FT	1,079	47.3	39.7	13.0
	PT	226	46.9	44.7	8.4
Pre-dialysis education	FT	1,072	43.7	48.6	7.7
	PT	227	53.3	39.2	7.5
Staff education	FT	1,069	10.9	82.5	6.6
	PT	219	16.0	80.8	3.2
Quality improvement	FT	1,077	13.2	82.4	4.4
	PT	227	18.1	78.4	3.5
Hospital discharge planning	FT	1,067	79.2	16.7	4.1
	PT	224	79.5	18.3	2.2
Collecting copays	FT	1,071	81.4	14.8	3.8
	PT	226	84.1	13.7	2.2
Treatment scheduling	FT	1,073	59.3	37.7	3.0
	PT	227	67.0	32.6	0.4

Note. FT = full time. PT = part time. *n* = subsample.

available time to provide psychosocial services to your patients as required by the Conditions for Coverage? and 2) Do you have clerical assistance on a regular basis for non-clinical tasks? No significant differences were found between the two groups of respondents. However, 70.4% of part-time and 76.6% of full-time workers reported insufficient time to provide psychosocial services as required by the CfC. In addition, 56.1% of part-time and 58.7% of full-time respondents indicated that they do not have clerical assistance on a regular basis.

DISCUSSION

This article examined the influence of the 2008 CfC on dialysis social workers' caseloads, job tasks, and hourly wages. In addition, it assessed their levels of responsibility for specific job tasks and their satisfaction with key work-related factors. The findings from this national study demonstrate clearly that part-time and full-time dialysis social workers have experienced notable increases in their patient caseloads (> 40%) and dramatic increases in their required job tasks (> 80%) since the implementation of the 2008 CfC. Together, these work demands represent a continuing challenge and area of concern for dialysis social workers (Browne, 2012; Merighi & Ehlebracht, 2004a, 2004b, 2004c; Wolfe, 2011), and have become more salient since 2008 (Merighi & Collins, 2011). Workload demands such as high caseloads (M = 130 for respondents who perceived an increase since 2008) and mounting job responsibilities as identified in this study make it difficult for

Table 7. *Employer-Provided Benefits for Full- and Part-Time Dialysis Social Workers*

Does your employer . . .	Work status	*n*	Yes (%)	No (%)	Don't know (%)
Provide health insurance***	FT	1,080	99.2	0.8	—
	PT	223	91.5	8.5	—
Provide vacation/sick pay	FT	1,073	98.3	1.7	—
	PT	224	96.0	4.0	—
Provide 401K/403B retirement plans	FT	1,075	92.4	7.6	—
	PT	221	87.8	12.2	—
Pay for gas/mileage*** reimbursement	FT	1,079	82.1	15.9	2.0
	PT	226	71.3	24.3	4.4
Provide paid time off to attend conferences	FT	1,078	77.6	22.4	—
	PT	227	67.8	32.2	—
Provide holiday pay	FT	1,076	58.2	41.8	—
	PT	222	53.2	46.8	—
Provide merit pay increases	FT	1,063	57.2	42.8	—
	PT	222	54.5	45.5	—
Provide profit sharing	FT	1,072	57.3	42.7	—
	PT	223	45.7	54.3	—
Pay for local educational conference registration	FT	1,077	51.4	40.9	7.7
	PT	224	44.7	45.5	9.8
Provide bonuses	FT	1,076	45.9	54.1	—
	PT	220	37.3	62.7	—
Provide yearly cost-of-living raises	FT	1,076	40.1	59.9	—
	PT	223	43.0	57.0	—

(continued)

Table 7. *Employer-Provided Benefits for Full- and Part-Time Dialysis Social Workers (Continued)*

Does your employer . . .	Work status	*n*	Yes (%)	No (%)	Don't know (%)
Pay for national education conference registration	FT	1,078	30.7	51.7	17.6
	PT	224	25.4	56.3	18.3
Provide a traditional pension plan	FT	1,073	16.7	83.3	—
	PT	218	20.6	79.4	—
Pay for online continuing education units	FT	1,084	15.6	62.8	21.6
	PT	227	15.0	64.3	20.7
Provide increased pay for licensure	FT	1,061	15.0	85.0	—
	PT	219	14.6	85.4	—
Pay for professional association dues	FT	1,079	12.4	77.1	10.5
	PT	226	14.2	75.6	10.2
Pay for NKF-CNSW Nephrology Social Worker Certification fee	FT	1,084	7.6	67.9	24.5
	PT	227	7.9	66.5	25.6
Pay for state licensure dues	FT	1,083	4.7	87.3	8.0
	PT	224	1.8	92.8	5.4
Provide increased pay for NKF-CNSW Nephrology Social Work Certification	FT	1,087	1.1	71.8	27.1
	PT	227	0.9	72.2	26.9

Note. FT = full time. PT = part time. *n* = subsample. ****p* < .001.

social workers to satisfy CfC mandates, given that their job expectations were already arduous prior to implementation of the 2008 CfC regulations. Additional work is needed to understand how the new CfC and ever-changing social worker-to-patient staffing ratios (see Wolfe, 2011 for an analysis of staffing ratios) affect patients' quality of care and health outcomes.

With regard to hourly wages, full-time dialysis social workers who reported an increase in their wages made significantly more per hour than social workers whose wages stayed about the same since 2008 (difference = $1.65 per hour). Interestingly, full-time social workers who reported a decrease in their caseloads reported making slightly less than those whose wages increased, $28.04 vs. $28.55 (see Table 3). It is unclear why this discrepancy exists, and why social workers who did not experience a change in their wages reported making the least per hour on average (i.e., $26.90). As expected, when examining hourly wage by level of satisfaction with pay, social workers who were dissatisfied made significantly less then social workers who were satisfied (difference = $1.95).

Mounting job tasks, increasing caseloads, and limited time to provide psychosocial services to patients and their families can manifest in job dissatisfaction for social workers in dialysis settings. It is evident from the survey findings that a substantial percentage of dialysis social workers (37%–49%) are dissatisfied with their caseloads, and that more than half are dissatisfied with their job tasks (50%–53%). Research on dialysis social workers prior to the 2008 CfC indicated that the majority of social workers reported average-to-high levels of overall job satisfaction (Merighi & Ehlebracht, 2004a). Current levels of satisfaction may be declining as the demands associated with the 2008 CfC challenge social workers to meet time-consuming Federal mandates and provide more services to a greater number of patients.

More than 70% of part-time and full-time respondents in this study reported that they do not have enough time to provide psychosocial services (including counseling) as required by the CfC. This finding may be due in part to the time needed to administer the KDQOL-36 and work closely with the interdisciplinary team so that all CfC-mandated tasks are completed. The 2008 CfC seem to have created an exponential increase in required tasks and constrained opportunities for social workers to develop supportive or therapeutic relationships with their patients. These relationships are an essential part of effective social work practice because they provide the foundation for improving patients' health outcomes and quality of life. The overemphasis on non-clinical tasks erodes dialysis social workers' practices and results in suboptimal care for ESRD patients because there is little opportunity for their complex psychosocial needs to be addressed by social workers. Research has demonstrated how nephrology social work interventions can help improve patients' psychological well-being and psychosocial adjustment (Beder, 1999; Dobrof et al., 2001; McCool et al., 2011; Sledge et al., 2011). It is clear that efforts are needed to rethink dialysis social workers' current job responsibilities (see Table 6) and caseload sizes so that they can use to full advantage their specialized knowledge and skills in order to provide comprehensive psychosocial services that are in the best interests of patients' physical health and psychosocial well-being.

The three main limitations of the current study include: 1) the cross-sectional research design; 2) selection bias; and 3) an inability to conclude with absolute certainty that changes reported by the respondents are a direct result of the 2008 CfC. This investigation used a cross-sectional design, which is a common practice in survey research studies. Unfortunately, it obtained information at one point in time and did not capture social processes or change. Social workers may have responded to items based on their experiences on the particular day they completed the survey, and these experiences may not be reflective of their usual work in their dialysis facility. Also, obtaining participation from only one professional organization limits the external validity of the findings. There may be selection bias with our sample because data on non-respondents are not available. Finally, it is assumed that respondents attributed changes in their practice to the implementation of the 2008 CfC. However, the increasing prevalence of dialysis patients, changing patient and family expectations, organizational restructuring, and new policies and procedures in dialysis facilities could have influenced the respondents either positively or negatively, regardless of the 2008 CfC. Despite these limitations, this remains an important national study of the state of nephrology social work practice in dialysis facilities since the implementation of the 2008 CfC. As such, this study provides important data for future investigations.

Additional research efforts are needed to monitor how the 2008 CfC will continue to influence social workers' job-related experiences, workload demands, and satisfaction in dialysis facilities. The findings reported here clearly demonstrate that many dialysis social workers are burdened with large caseloads and an increasing number of job tasks since the implementation of the 2008 CfC. Studies are needed to assess the degree to which these factors are affecting, either positively or negatively, the delivery of psychosocial services to dialysis patients and their families. Also, it is unclear if a greater number of dialysis social workers are experiencing feelings of burnout or thoughts of leaving their jobs as a result of the increased work-related demands associated with the 2008 CfC. Empirical investigations are needed to examine these critical issues so that interventions can be developed to protect the occupational well-being of social workers in nephrology settings. In addition, researchers, nephrology social work practitioners, and dialysis administrators need to join together to develop effective ways to meet Federal mandates and workplace requirements without jeopardizing dialysis patients' psychosocial needs or social workers' abilities to provide high-quality social services and clinical counseling. More innovative approaches are needed to create healthy, supportive, and collaborative work environments that enable social workers to provide essential psychosocial services to people with end-stage renal disease in the most effective and compassionate manner possible.

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Patient-Centered Advance Care Planning in Dialysis: Phase One

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Due to the high mortality rates and significant symptom burden of dialysis patients, attention to advance care planning (ACP) has grown in the nephrology community. The optimal system for addressing ACP in dialysis units is not known. We report a quality initiative project utilizing a multidisciplinary ACP team, aiming to address ACP in the outpatient dialysis unit setting in a systematic and timely manner. The results suggest that a dedicated ACP program in the dialysis unit setting is a potentially valuable tool for improving advance directive (AD) completion rates in severely ill dialysis patients. Further research of such patient-centered interventions for improving the quality of care of severely ill dialysis patients is warranted.

Background and Significance

Despite significant advances in dialysis technology, end-stage renal disease (ESRD) patients have a significant annual mortality rate in excess of 20% (USRDS, 2009). Arnold and Zeidel (2009) noted that, “mortality in this population is so high that it resembles a group of patients with an incurable cancer” (p. 1597). Many ESRD patients experience a significant decline in quality of life as a result of high symptom burden often reported at the end of life (Weisbord, et al., 2005). The dialysis population represents 1% of the Medicare population and accounts for 7% of the Medicare budget; however, many dialysis patients die in hospitals, without hospice services and with significant symptoms of distress and pain (Murray, Arko, Chen, Gilbertson, & Moss, 2006).

In this population, discussions on end of life are often delayed until late in the course of the disease and held in times of crisis, leaving little time for implementing effective end-of-life care (Davison, 2010). Dialysis patients do not receive the end-of-life care they want or need because of either non-existent or poorly designed advance care planning (ACP) interventions (Butcher, 2010). Evidence suggests that patients and family members value early discussions about prognosis, treatment options, and how to prepare for end of life (Holley, 2005; Weisbord et al., 2003). Furthermore, early discussions surrounding end of life and completion of advance directives (AD) in dialysis patients can improve patient quality of life and quality of death (Swartz & Perry, 1993; Weisbord et al., 2003).

Despite fragmentation and inconsistency of ACP in dialysis, guidelines and tools do exist to support successful implementation of programs. Recent parameters for identifying dialysis patients at high risk for dying have been published and can be used as a valuable tool in the ACP intervention process (Cohen, Ruthazer, Moss, & German, 2010). Despite these well-known strategies and interventions aimed at improving quality of life, implementation of ACP programs in dialysis units are not prevalent in the renal community (Moss, 2003). Furthermore, little is known about the effects of in-center patient-focused ACP that utilizes these guidelines and tools.

Although an optimal system for addressing ACP in dialysis units is unknown, we report a quality initiative project utilizing a multidisciplinary ACP team and prognostic indicators to provide effective interventions to patients determined to be at high risk for dying in the dialysis unit. The aims of this initiative involved: 1) creating a framework for addressing ACPs consistently; 2) bridging communication between patients, dialysis staff, the primary care provider (PCP), inpatient providers, and palliative care specialists; 3) creating a multifaceted documentation tool for ACP; and 4) shifting the paradigm of addressing ACP from the inpatient to the outpatient setting.

LITERATURE REVIEW

Patients with ESRD represent a special group of individuals who require comprehensive care that includes planning for end of life. The dialysis population has a shortened life expectancy and symptom burden unlike any other chronically sick population. Growing evidence suggests that the quality of life for dialysis patients at the end of life is less than optimal (Chater, Davison, Germain, & Cohen, 2006; Cohen, Germain, Poppel, Woods, & Kjellstrand, 2000). Researchers have noted the need for more comprehensive approaches to care that improve how practitioners identify patients’ end-of-life needs and how they implement end-of-life interventions in the dialysis unit setting (Cohen, Germain, Woods, Mirot, & Burleson, 2005; Cohen et al., 2000; Chambers, Germain & Brown, 2004; Emnett, Byock, & Sheils Twohig, 2008). Furthermore, the use of prognostic indicators to identify patients appropriate for palliative care referrals is becoming of more interest to researchers and practitioners as more attention is placed on the significant needs of this population (Cohen et al., 2010).

Note: This study was conducted at the Geisinger Medical Center Outpatient Hemodialysis Unit, 100 Justin Drive, Danville, PA 17822, and the Geisinger Nephrology Clinic, 100 Academy Avenue, Danville, PA 17822.

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Advance Care Planning in Dialysis

Patients with ESRD are often well known to their renal care team due to years of treatment on dialysis and intimate discussions regarding goals of care and symptom management. Ideally, discussions regarding end-of-life care should occur at the beginning stages of dialysis rather than at the end stages of life. Numerous opportunities exist to improve how renal professionals approach end-of-life care planning with dialysis patients at diagnosis and throughout treatment. Furthermore, studies show that patients and families are likely more willing to talk about end-of-life issues than expected (Davison, 2006; Davison, 2010; Moss, 2011). Patients report that they desire more communication and information earlier in their illness about prognosis, how long they can expect to be on dialysis, and what the impact of treatment will be on their daily lives (Russ, Shim, & Kaufman, 2007).

The unique circumstances of this chronically ill population, including the accessibility of patients to staff on a weekly basis in a medical setting, provide extensive opportunities for renal medical teams to develop patient-centered interventions. In the dialysis unit, patients and caregivers have rare opportunities to discuss how patients want to live, what quality of life they want to have, and how they can prepare for the end of life. ESRD patients express much confidence in their renal care team to manage symptoms, address ACP, and provide psychosocial and spiritual support in a timely and effective manner (Davison, 2010). It has been recommended that such planning should emphasize patient and family emotions and focus more on goals of care and less on specific treatments (Tulsky, 2005).

Barriers to Implementation

Despite reports and recommendations for dialysis centers to implement standardized ACP tools, the benchmarks to guide ACP in dialysis units vary among facilities, and are at times non-existent (Davison, 2006; RPA & ASN, 2010). The development and success of ACP for dialysis patients is reported to be challenging because of the sensitive nature of end-of-life issues, coupled with emotional barriers of staff, patients and families. Other challenges include the uncertainty of timing of intervention, inconsistent professional roles, and apprehension among nephrologists about providing early end-of-life interventions without clearly defined prognostic tools (Cohen et al., 2010; Davison & Simpson, 2006; Parascandola, Hawkins, & Danis, 2002). Studies show that the most troubling ethical issues for nephrologists involve starting and stopping dialysis (Cohen, Moss, Weisbord, & Germain, 2006). Furthermore, the postponement of such discussions can lead to urgent decision making, when death seems imminent (Quill, 2000).

Best Practices

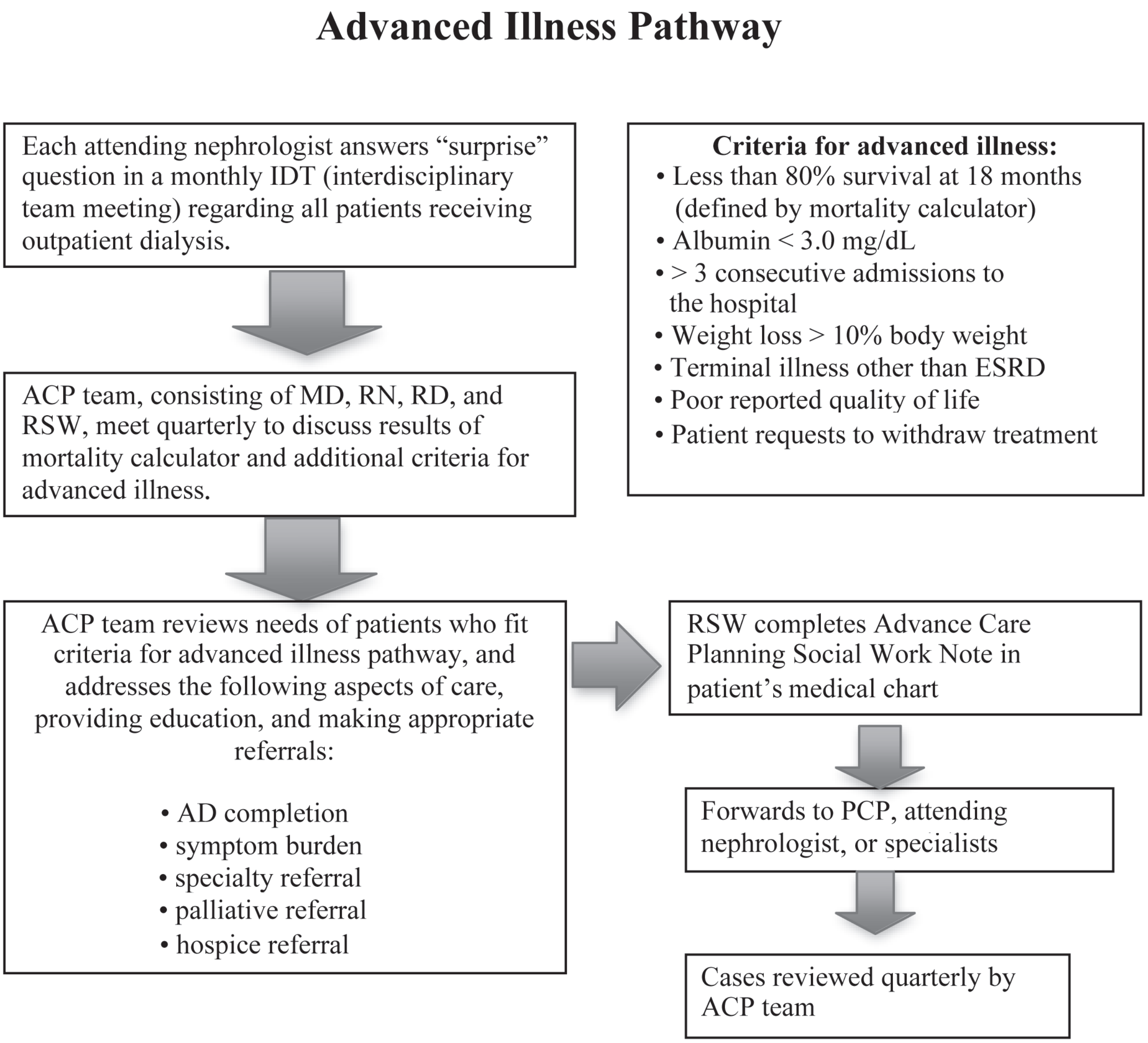
Extensive guidelines and recommendations for best practices concerning dialysis patients and ACP are available to renal care providers (Davidson & Torgunrud, 2007; Moss, 2003; RPA & ASN, 2010). However, little research has been done regarding the significance or implementation of ACP pathways in the dialysis unit. Professionals have recommended ACP guidelines that can be used to develop systematic pathways for the dialysis unit setting (Cohen et al., 2010; Davison, 2010; Davison & Torgunrud, 2006; Saini, Murtagh, Dupont, McKinnon, Hatfield, & Saunders, 2006). Despite the diversity in pathways among units, given patient caseload, organizational structure, and staffing, the recommended guidelines provide a framework from which units can develop effective ACP interventions that align with the needs of patients and the agency. Figure 1 represents the Advanced Illness Pathway that was developed for this study and includes both recommended RPA guidelines and goodness of fit for the unit.

Despite existing barriers to implementation of early ACP in dialysis, it is suggested that a multidisciplinary approach to intervention is likely most effective, given the all-encompassing needs of this population (Fasset, Robertson, Mace, Youl, Challenor, & Bull, 2011; Moss, 1997; RPA & ASN, 2010; Young, 2009). Berzoff, Swantkowski, and Cohen (2008) concluded that there needs to be greater education of both patients and families regarding all aspects of the disease process; open communication; ongoing support between patients, families and the staff; continuity of care; pain control; and assistance with ACP. Furthermore, research has indicated that ACP interventions in the dialysis population can lead to desirable outcomes such as a good death, improved sense of hope, and decreased physical suffering (Davison, 2006; Swartz & Perry, 1993; Weisbord et al., 2003).

Emerging evidence suggests that early ACP interventions, guided by validated prognostic indicators and using a multidisciplinary approach, are likely to improve patient quality of life and quality of death (Cohen et al., 2006; Davison, 2010; Holley, 2005; Moss et al., 2008). In order to identify patients with poor prognosis who would benefit from palliative interventions, ACP, and psychosocial, spiritual and bereavement support, there is an increasing demand for more accurate and simple prognostic indicators (Cohen et al., 2006). The mortality calculator is an integrated prognostic model that appears to be a "good fit" for the dialysis population (Cohen et al., 2010). The use of the mortality calculator enables the practitioner to identify more accurately and earlier in the stages of advanced illness a poor prognosis, when referrals to hospice or palliative medicine may be appropriate. The components of the mortality calculator include age, diagnosis of dementia, peripheral vascular disease (PVD), albumin level, and the "surprise question." This prognostic model "lends itself to risk stratification of patients, it is more specific and sensitive than any of its components, and it seems to be a considerable improvement over other existing instruments at predicting survival in the dialysis population" (Cohen et al, 2010, p. 78).

There is existing research that supports the integration of prognostic indicators with early end-of-life planning for

Figure 1. *Flow Chart of Advanced Illness Pathway*



Advanced Illness Pathway

Each attending nephrologist answers "surprise" question in a monthly IDT (interdisciplinary team meeting) regarding all patients receiving outpatient dialysis.

ACP team, consisting of MD, RN, RD, and RSW, meet quarterly to discuss results of mortality calculator and additional criteria for advanced illness.

ACP team reviews needs of patients who fit criteria for advanced illness pathway, and addresses the following aspects of care, providing education, and making appropriate referrals:

- AD completion
- symptom burden
- specialty referral
- palliative referral
- hospice referral

Criteria for advanced illness:

- Less than 80% survival at 18 months (defined by mortality calculator)
- Albumin < 3.0 mg/dL
- > 3 consecutive admissions to the hospital
- Weight loss > 10% body weight
- Terminal illness other than ESRD
- Poor reported quality of life
- Patient requests to withdraw treatment

RSW completes Advance Care Planning Social Work Note in patient's medical chart

Forwards to PCP, attending nephrologist, or specialists

Cases reviewed quarterly by ACP team

Key: ACP, advance care planning; AD, advance directive; ESRD, end-stage renal disease; IDT, interdisciplinary team; MD, medical doctor; PCP, primary care physician; RD, registered dietitian; RN, registered nurse; RSW, renal social worker dialysis patients; however, there are limited studies on the effects of such an approach. The patient-centered approach described in this paper allows for practice that systematically addresses the pervasive needs of both patients and families.

Systematic integration of ACP into dialysis units is a process of sharing information among patients, families, and renal care teams that involves understanding and communication to help patients and family members make end-of-life care decisions (Davison, 2006).

A team approach to intervention ensures effective use of resources in a challenging, always-changing treatment environment. The value of this team approach for dialysis patient care is well documented (Browne, 2012; Porter, 2007; Prescott, 2006; U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, 2008). However, there is scant information regarding its potentially significant benefits for ACP in dialysis settings.

Dialysis professionals provide specialized care throughout the course of a patient's illness, and often until death. Treatment is focused on the medical, nutritional, technical, and psychosocial aspects of care. These significant areas of care are no different in patients with poor prognosis. The lack of a documented multidisciplinary, ACP approach is surprising. The recommended prognostic indicator (i.e., mortality calculator) is multidisciplinary, as its aspects include medical, psychosocial, and nutritional care. Best practice ought to mirror this prognostic tool. This research supports this assertion. Increased attention to this approach to ACP intervention is likely to lead to more positive patient and family outcomes.

STUDY PURPOSES

Given that little research has been conducted on the benefits of ACP in the dialysis unit setting, we conducted a quality improvement (QI) initiative to explore the feasibility of a systematic, multidisciplinary, patient-centered approach to ACP. The purpose of this initiative was to implement a systematic approach to ACP intervention that utilized the expertise of multidisciplinary team members in conjunction with prognostic indicators (i.e., the mortality calculator) to provide a more proactive and patient-focused approach to end-of-life care. At the conclusion of the QI initiative, IRB approval was received to collect data retrospectively in order to evaluate outcomes. Outcomes of interest included: 1) value of prognostic indicator in identifying patients at high risk for dying; 2) frequency of events prior to death such as hospitalizations, referrals to hospice, and referrals to palliative medicine; and 3) AD completion rates.

METHOD

Development of ACP Team

This project started as a quality improvement initiative aimed at several components of ACP in a rural tertiary hospital-affiliated outpatient dialysis unit. An ACP team was assembled in August 2010, consisting of a nephrologist (MD), renal social worker (RSW), unit registered nurse team leader (RN), and a renal dietitian (RD). The team proactively estimated the prognosis of all prevalent dialysis patients, and met quarterly throughout the year to discuss and identify areas of patient need based on their probability of survival. At the monthly dialysis unit's interdisciplinary team (IDT) meetings, attended systematically by a nephrologist and at least two members of the team (RSW and RN), the rounding nephrologists were routinely asked the surprise question, "Would you be surprised if your patient would die in the next 6 months?" Then, specific recommendations on prognosis and ACP were developed. Clinical assessments, combined with prognostic indicator outcomes, were used to identify medical and social needs of patients, and to make appropriate health care and community referrals.

Prognostic Indicators

Rounding nephrologists were each asked systematically during monthly IDT meetings if they would be surprised if their patient would die in 6 months. A "no" answer to the "surprise" question, conferred a 3.5 higher odds of dying within 1 year, in a prospective cohort of 147 patients at 3 hemodialysis units (Moss et al., 2008). The prognosis of prevalent dialysis patients was then estimated monthly using an available prognostic tool endorsed by available guidelines [available at **http://touchcalc.com/calculators/sq**] (RPA & ASN, 2010). This online survival estimator tool for dialysis patients was developed, based on the study of Cohen et al. (2010), and uses several simple, readily available parameters (age, serum albumin, presence or absence of dementia and/or peripheral vascular disease, and the answer to the "surprise" question). This prognostic model was developed in a large cohort of prevalent dialysis patients and was prospectively validated with an excellent area under the curve of 0.80 (95% CI 0.73 to 0.88) in another validation cohort of 514 patients from 8 dialysis clinics (Cohen, 2010).

Usual Care in Our Dialysis Unit

All patients in the unit receive standard AD education at admission and yearly thereafter, or with a change of clinical condition. Monthly interdisciplinary team meetings are held as per Centers for Medicare & Medicaid Services (CMS) guidelines. Family conferences and referrals to palliative medicine or hospice are made at the discretion of primary nephrologists. Patients who express their desire to stop dialysis are evaluated and screened for psychosocial interventions by the unit social worker, and appropriate specialty referrals are requested at the discretion of the primary nephrologists.

Advanced Illness Pathway (AIP)

The Advanced Illness Pathway is a biopsychosocial tool that instructs dialysis professionals on how to assess and treat patients who are identified as high risk for dying. Prevalent dialysis patients were selected for the advanced illness pathway (AIP) if nephrologists had a negative answer to the surprise question, or if patients' probability of survival at 18 months was less than 80% per the mortality calculator; if they had more than three admissions to the hospital a period of 30 days; a weight loss of more than 10% body weight; a diagnosis of a terminal illness other than ESRD; poor reported quality of life; or if they requested to withdraw from dialysis treatment.

Patients in the AIP were systematically asked whether they had ADs and were provided with education regarding ACP. When AD were not available or completed, the social worker met individually with the patients and their families and provided additional education and support during dialysis hours with additional phone calls during off hours.

Conferences between patients, families, and staff, including primary nephrologists, were facilitated by the ACP team when conflicts regarding goals of care were perceived or if additional information for decision making was felt necessary.

Documentation

A "template-ed" note entitled, "The Advance Care Planning Social Work Note," was completed in the dialysis unit electronic health record (EpicCare™) at patient enrollment in the AIP; after each interdisciplinary team meeting; and when patients' conditions changed. The forms contained the dialysis team's assessment and recommendations regarding ADs, referrals to palliative care, or changes in code status (see Figure 2). The notes were submitted for review, edited, and electronically signed by the rounding nephrologists, and then electronically filed and sent by the social worker to primary care physicians and other key subspecialty physicians involved in patients' care.

Data Collection

Demographic and clinical data for estimation of survival was collected prospectively in an MS Excel database accessible to all ACP team members. The ACP team reviewed aggregate results of patient data quarterly.

Patients names were censored at death or at the end of the study, whichever occurred first. Outcomes of interest for our dialysis unit were: AD completion rates, referrals to palliative medicine, number of hospitalizations prior to death, and referrals to hospice. The study was approved by the Geisinger Internal Review Board.

Data was analyzed using descriptive statistics (i.e., means, modes, standard deviations).

RESULTS

Between August 1, 2010, and August 1, 2011, 105 patients received dialysis at the Justin Drive GMC Dialysis unit in Danville, PA. Sixteen patients (15%) died in our unit during the 12 months of followup.

Twenty-eight patients were excluded from the study: 16 transferred to other dialysis centers during the follow up; 4 changed to a home treatment modalities; 3 recovered renal function; 4 received a kidney transplant; and 1 died unexpectedly.

Of the remaining 77 prevalent patients reviewed, 48 met criteria for advanced illness and were included in the AIP group. 29 patients met the criteria for the non-AIP group. Demographic and clinical characteristics of these patients are presented in Table 1. Relevant variables of interest of the prevalent dialysis patients are presented in Table 2.

The mean 18-month estimated survival at enrollment in the AIP group was 56.5% (S.D. 23.8), compared with 90% (S.D. 4.2) in the other patients in our unit. Overall, AD completion rate for prevalent patients in our unit increased from 28.5 % (22 of 77) at baseline to 48% (37 of 77) at 1 year. In the AIP group, AD completion increased from 29% (14 of 48) dialysis patients to 60% (29 of 48) at 1 year.

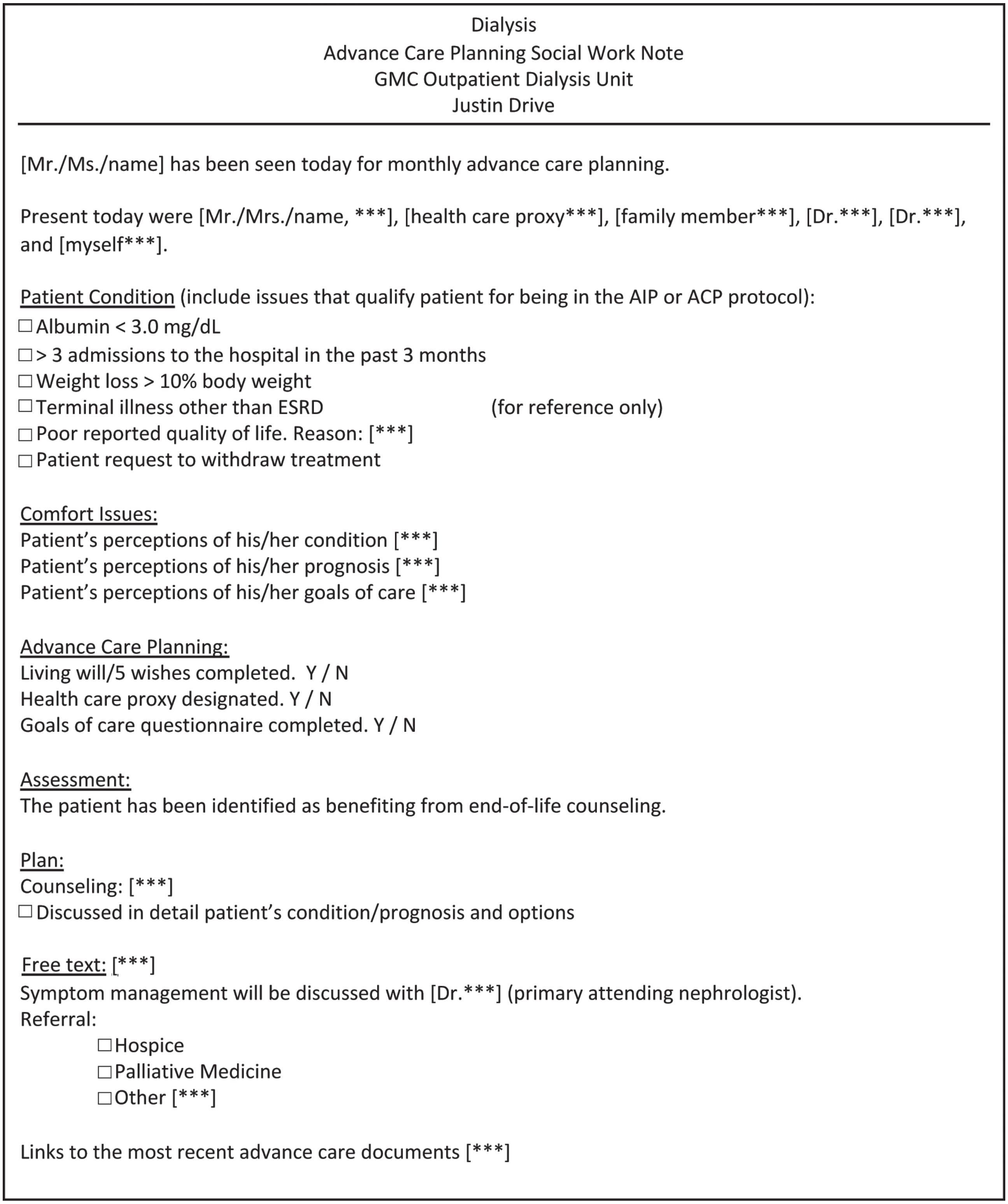
During the follow-up period, 16 prevalent patients (19.2% of the AIP group) ages 62 to 88, of which 8 were men, died. Of these, 14 (87.5%) were identified to have a survival of less than 80% at 18 months (qualifying for the AIP pathway) and 2 (12.5%) who did not meet the AIP guidelines died unexpectedly. Important patient-centric outcomes in the deceased patients in both groups are presented in Table 3. In the deceased patients in the AIP group, AD completion increased from 5/14 (37.7%) to 11/14 (71.4%) during the year of follow up, 9 (64.2%) were hospitalized within one month prior to death, 7 (50%) were referred to hospice, and 4 (28.5%) were referred to palliative medicine prior to demise.

DISCUSSION

The data from our quality initiative project suggests that a multidisciplinary team approach involving proactive identification of dialysis patients with advanced illness, as well as a systematic persistent approach to ACP, has a positive impact on AD completion rates in a hospital-affiliated dialysis unit. It is evident this study demonstrates that a patient-centered multidisciplinary approach to ACP is of value to the dialysis population. Further integration of palliative medicine into the dialysis unit setting is warranted given these findings.

Given the heterogeneity of dialysis patients, it seems unlikely that renal professionals will be able to provide a single universal ACP protocol that is applicable to all dialysis patients. Still, the value and benefits of early ACP are likely to have a significant impact on overall patient quality of life through early referrals to palliative medicine and

Figure 2. *Advance Care Planning Social Work Note*



Dialysis
Advance Care Planning Social Work Note
GMC Outpatient Dialysis Unit
Justin Drive

[Mr./Ms./name] has been seen today for monthly advance care planning.

Present today were [Mr./Mrs./name, ***], [health care proxy***], [family member***], [Dr.***], [Dr.***], and [myself***].

Patient Condition (include issues that qualify patient for being in the AIP or ACP protocol):
☐ Albumin < 3.0 mg/dL
☐ > 3 admissions to the hospital in the past 3 months
☐ Weight loss > 10% body weight
☐ Terminal illness other than ESRD (for reference only)
☐ Poor reported quality of life. Reason: [***]
☐ Patient request to withdraw treatment

Comfort Issues:
Patient's perceptions of his/her condition [***]
Patient's perceptions of his/her prognosis [***]
Patient's perceptions of his/her goals of care [***]

Advance Care Planning:
Living will/5 wishes completed. Y / N
Health care proxy designated. Y / N
Goals of care questionnaire completed. Y / N

Assessment:
The patient has been identified as benefiting from end-of-life counseling.

Plan:
Counseling: [***]
☐ Discussed in detail patient's condition/prognosis and options

Free text: [***]
Symptom management will be discussed with [Dr.***] (primary attending nephrologist).
Referral:
  ☐ Hospice
  ☐ Palliative Medicine
  ☐ Other [***]

Links to the most recent advance care documents [***]

Table 1. *Baseline Demographic and Clinical Characteristics of the Prevalent Dialysis Patients*

Demographics	**AIP Group** (*n* = 48)	**Non-AIP Group** (*n* = 29)
Females (%)	23 (47.9)	10 (34.4)
Median Age (S.D.)	76 (9.7)	58.2 (13.6)
Caucasians (%)	100	93
Median time (months) on dialysis (S.D.)	37.7 (39.8)	53.5 (44.4)
Comorbid conditions n (%)		
Congestive heart failure	38 (79.1%)	12 (41.3%)
HTN	39 (81.2%)	27 (93.1%)
Peripheral vascular disease	5 (10.4%)	3 (10.3%)
Diabetes	28 (58.3%)	12 (41.3%)
Cancer	6 (12.5%)	5 (17.2%)
Dementia	4 (8.3%)	0

N = 77

Table 2. *Relevant Variables of Interest of Prevalent Dialysis Patients*

	AIP Group *(n = 48)*	**Non-AIP Group** *(n = 29)*
Relevant variables of interest as of 8/1/2010		
Advance directives completed	14	8
Relevant variables of interest as of 8/1/2011		
Deaths	14	2
Total number of hospitalizations during 12 months	67	20
Hospitalized within 30 days prior to death	11	2
Palliative care referrals	7	0
Hospice referrals	6	0
Advanced directives completed	29	8

Table 3. *Observed Values of End-of-Life Indicators for Deceased Patients*

End-of-Life Indicators	**AIP Group** *(n = 14)*	**Non-AIP Group** *(n = 2)*
Mean initial predicted survival at 18 months (S.D.)	41.3% (28)	88.5% (7.8)
Mean initial predicted survival at 12 months (S.D.)	55.3% (27.9)	93% (4.2)
Mean initial predicted survival at 6 months (S.D.)	75.4% (21.1)	97.5% (2.1)
Advance directives at start of QI Project	37.7%	50%
Advance directive prior to death	71.4%	100%
Hospitalized at 30 days or < before death	64.2%	100%
Referred to hospice before death	50%	0%
Referred to palliative medicine before death	28.5%	0%

Key: S.D. = standard deviation

hospice, and early discussions surrounding patient goals for end of life. More research is needed to investigate the value of ACP for dialysis patients who are at high risk for dying, particularly as it relates to outcomes for patients, families, and renal care providers. Despite evidence that hospice in ESRD patients leads to decreased reports of pain, improved quality of life and considerable cost savings, research suggests that ESRD patients and family members have end-of-life care preferences and needs that continue to be unmet (Davison, 2010; Davison & Simpson, 2006; Murry, et al., 2006; Thompson, Bhargava, Bachelder, Bova-Collis, & Moss, 2008).

There are also potential benefits associated with early ACP intervention for renal providers, such as improved job satisfaction, and decreased compassion fatigue. However, little information exists regarding the relationship between dialysis staff "burnout" rates and patients' end-of-life care needs. As the dialysis environment continues to evolve in response to the aging population and the changing work environment, awareness of the effects of ACP programs on staff outcomes will likely increase.

Successful future interdisciplinary ACP initiatives will benefit from education and support for all dialysis unit staff. For this ACP project, the primary interdisciplinary care team, along with front-line dialysis nursing and technician staff, were educated regarding the initiative and provided with support and information to ensure consistency regarding end-of-life interventions and care. Overall, staff reported increased comfort knowing that there was an initiative in the unit to address patients' end-of-life needs. During this initiative, staff also responded favorably to the protocol and integrated the ACP initiative into their practices. Although no formal assessment was completed to investigate the responses of patients and family members to the initiative, members of the ACP team, along with dialysis staff, reported that patient and family members appreciated having the opportunity to discuss end-of-life care, including pain control, ADs, and information regarding palliative and hospice care.

As the implementation of ACP programs in dialysis units is increasing, how patients and providers view ACP will greatly depend upon how renal care teams can help patients to overcome misconceptions regarding ACP, end of life, quality of life, and quality of death. The introduction of ACP at the initiation of dialysis, rather than at the "withdrawal stage," offers a more systematic approach in keeping with a continuum of care over time. This is more patient-centered, targeted at reducing symptom burden and increasing of quality of life. The relationship between early ACP, adverse outcomes (e.g., hospitalizations), and a good death is an important aspect of dialysis treatment and requires further exploration to ensure effective interventions and positive outcomes for patients and the health care community.

Renal care teams will continue to play an integral part in developing and implementing patient-centered ACP programs. An interdisciplinary approach, coupled with utilization of recommended prognostic indicators and clinical guidelines, in addition to ongoing comprehensive reviews of patients' needs and the health care environment, will ensure best practices in the dialysis unit setting.

FUTURE GOALS

Desired short- and long-term outcomes for the project include: 1) improved patient/family quality of life; 2) improved communication among health care providers in the Geisinger System; 3) decreased hospitalizations; 4) improved quality of mortality; 5) improved AD completion rates; 6) improved staff coping abilities; 7) introduction of a second phase of the initiative involving the integration of palliative medicine as an adjunct to outpatient dialysis care; and 8) application of the KDQOL-36 as an additional prognostic tool for hospitalization and mortality.

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Social Media: Examination of Renal Professional Practices and Guiding Principles

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The widespread use of technology and social networking websites, such as Facebook and Twitter, creates new avenues for renal professionals to share information. However, intentional or unintentional virtual contacts with patients and potential breaches of professional ethics are always possible. During a session at the NKF 2012 Spring Clinical Meetings in Washington, D.C., attendees discussed ethical dilemmas in this era of rapidly expanding social media, were polled regarding their practices, and expressed the need for further examination of the implications of new technologies for renal patients, professionals, and organizations. By seeking consultation with regard to ethics and reviewing professional, regulatory, and agency policies, health care professionals can stay on the safe side of social media.

INTRODUCTION

A recent post on the Council of Nephrology Social Workers professional email LISTSERV inquired about how social workers handle "Friend" requests on Facebook from patients. This prompted a lively discussion of professional boundaries, dual relationships, and the need for further exploration of ethical practices and policies around this ever-changing social landscape (NKF CNSW LISTSERV, 2011). The purpose of this article is to examine the many challenges faced by social workers related to social networking, and to discuss some guiding principles.

What is social media? Social media is the use of web-based technology that allows the exchange of user-generated content. Facebook, the ubiquitous social networking utility, presently has 1 billion users (Facebook, 2012). Twitter claims 140 million users (Bennett, 2012; Wasserman, 2012). The majority of national renal professional organizations, patient organizations, and dialysis corporations now utilize Facebook and Twitter.

Facebook is a social networking service which requires users to register before using the site, after which they may create a personal profile, list other users as friends, and exchange messages, including automatic notifications when they update their profile. For those who are unfamiliar with Twitter, it is a microblogging service that allows users to send messages of up to 140 characters ("Tweets") to recipients known as "followers." While on Facebook, both parties must agree to be friends; with Twitter, users have limited control of who follows them. "Tweets" may be read by anyone, whether registered with Twitter or not.

Blogs are online journals written by one person or a group of contributors, often focused on a specific field or specialty. Blogs permit writers to engage in conversations with readers. There are many nephrology-related blogs, websites, and LISTSERVs: patient-authored, physician-authored, and university-based. The term "LISTSERV" has been used to refer to electronic mailing list software applications, allowing a sender to send one email to the list, which transparently sends the email to all addresses subscribed to the list.

With limited control of who reads or follows social networking content, intentional and unintentional virtual contacts between staff and patients are always possible. Some of the situations that may arise with new technology: emails between staff and patients; patients "Googling" (using the Google online search engine) staff; staff "Googling" patients; and issues of confidentiality and privacy. Information provided could be inadvertently used to identify a patient. The ease of posting and the commonplace nature of sharing information via social media may appear to blur the line between one's personal and professional life.

Advantages of Social Media

There are numerous advantages to having social networking accounts. Information can be disseminated quickly and to a large population at no cost. Social media is used for:

- A venue for online discussion of health-related topics and trends
- A bulletin board for posting upcoming events
- Fostering professional connections
- Marketing
- Sending, receiving, and accepting social invitations
- Sharing local, national, and international news
- Forging ties with out-of-state family and friends
- Exercising humor and creativity
- Sharing and receiving information relevant to lives and interests
- Keeping up with professional trends and contacts
- Participation in civic action, including advocacy and public policy

Renal Business Today (2010) featured the article "Social Media in Nephrology." The director of communications for DaVita provided comments in this article on social media: "This platform benefits doctors, caregivers, patients, and their loved ones in several ways: patients can share experiences and benefit from industry information to improve

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their quality of life, loved ones can share experiences and learn how they can offer better support, and the doctors/care team members can learn first-hand what their patients are looking for, giving them prime ways they can better their facilities—especially on a human level."

Risks Related to Social Networking

To understand the limits of appropriate use of social media, it is important to have an understanding of the risks faced by professionals. The National Association of Social Workers (NASW, 2005) and Association of Social Work Boards (ASWB) have developed the Standards for Technology and Social Work Practice to create a uniform document for the profession. The specific goals of the standards are:

- to maintain and improve the quality of technology-related services provided by social workers;
- to serve as a guide to social workers incorporating technology into their services;
- to help social workers monitor and evaluate the ways technology is used in their services; and
- to inform clients, government regulatory bodies, insurance carriers, and others about the professional standards for the use of technology in the provision of social work services.

The discussion of risks below, based on that guide, is not meant to be exhaustive or to reflect the order of importance.

Confidentiality—Information that is shared with staff by patients, including patients' identities, must remain confidential unless the patient authorizes release. This requirement could easily be violated through use of a website designed for social networking. Users run the risk of violating patients' privacy and confidentiality by disclosing too much information. Emails, LISTSERVs, social networking websites, tweets, and blogs are not private, and can easily be shared by the recipient with others. Even content that has been deleted is accessible. Some examples of potential privacy and confidentiality violations:

- There is always the risk of disclosing too much identifiable information. A mistaken belief is that it is acceptable to discuss or refer to patients if they are not identified by name, but referred to by a nickname, room number, diagnosis, or condition.
- If we "accept" a patient's "Friend request" (for instance on Facebook or LinkedIn), there is risk of possible exposure of the patient's identity to others. In order to make a "Friend" on Facebook, a user sends a "Friend request" to another user. If that user confirms that they are indeed friends, then the users appear on each other's Friend lists and they can send each other messages, write on each other's "walls" or pages, or chat. The identity and number of friends is displayed conspicuously, and is easily noticeable by anyone who looks at a person's Facebook page.
- What happens when your patient discovers you have 20 Facebook Friends in common? Will they wonder what you are sharing with these friends?

Dual relationships—The NASW Code of Ethics (NASW, 1996) stipulates that social workers should not engage in dual or multiple relationships, with clients or former clients, in which there is a risk of exploitation or potential harm to the client. Accepting an invitation from a client to be a friend on Facebook (or other social network sites) creates a dual relationship.

Effect on team-based patient care—Cyber-bullying, or the use of cell phones or other devices to send or post text or images intended to hurt or embarrass another person, is detrimental to a cohesive health care delivery team. For example, a member of the interdisciplinary care team sending "Tweets" about patients that are unprofessional in nature can result in a loss of therapeutic effectiveness, loss of objectivity, and exploitation.

Legal risks—What you learn about patients in social media could become a legal issue. What if a patient were to tweet about being suicidal? Could you be professionally liable for failing to prevent harm?

NKF SCM12 "Social Media and Boundaries" Session—Audience Response Results

Using audience response system technology, attendees at the NKF 2012 Spring Clinical Meetings session on May 12 in Washington, D.C. (Hall, 2012), were polled regarding their personal and professional use of social media. Respondents were a fairly even spread across ages, ranging from 20 to 70, with a few more attendees in their 20s (18 attendees, or 30%). Ninety percent were social workers, 5% nurses, and 5% were other renal professionals. Of those surveyed more than 45% stated they used social media on a daily basis, and only 27% stated they never used social media. Interestingly, the sample's use of social networks highlighted the many gray areas faced by renal professionals. Eleven percent reported receiving a "Friend request" from patients, with 7% reporting they accepted the request. Thirteen percent thought it was acceptable to engage patients on social networks, depending on the situation, while 22% were uncertain what to do if a previous patient tried to "Friend" them after treatment had been completed.

There are many doctors and facilities beginning to use social networking to expand their practices, utilizing platforms like Facebook, Twitter, and others as marketing tools. Common in these approaches is the use of patient testimonials, or asking patients to rate doctors on places like Angie's List or Yelp. When asked what to do when a renal patient "Likes" a Facebook page that is professionally oriented, attendee responses were split pretty evenly between choices (i.e., this is a breach of confidentiality; this is acceptable; and uncertain whether this is appropriate). The "Like" button is a Facebook feature where users can "Like" content such as status updates, comments, photos, links shared by friends, as well as advertisements, articles, and other online content.

One hypothetical situation that was posed to attendees: "You are friends with coworkers on Facebook. One posted photos of his birthday party, revealing that patients and other colleagues attended. Should you bring this to your clinical manager's attention?" Seventy-six percent responded yes, while the others either would not report the incident (13%) or were uncertain (11%). Some who responded "yes" commented that this seems like a pretty clear violation of boundaries, and they were surprised by the "no" and "uncertain" responses.

Another scenario inquired whether it is ethical to bring up questionable Facebook content with a patient. For instance, a woman three months pregnant posts a photo of herself with a cigarette in one hand and a beer in the other. Renal professionals were split on whether to confront the woman, though National Association of Social Workers Code of Ethics (NASW, 1996) state that social workers should respect clients' right to privacy, and should not solicit private information from clients unless it is essential to providing services. The fact that information about patients is available electronically through various search engines does not mean we should access it. Seeking information on the internet about a patient without his/her knowledge may violate an implied contract and erode the patient's sense of trust. Attendees debated whether a Facebook posting is indeed "private" and, in the case of the hypothetical pregnant woman, expressed concern about the rights of the fetus.

Attendees were also asked to consider the following question regarding a posting on a professional LISTSERV: "You post on the LISTSERV a dilemma you are facing with a particular patient at your facility. Your LISTSERV signature lists your facility address and affiliation. Is this patient potentially recognizable to LISTSERV members?" Eight-two percent responded "yes," 9% responded "no," and 9% were "uncertain." Attendees commented that examination of this issue created new awareness of the importance of guarding individual identifying information when corresponding by email.

It was clear from the audience discussion that, when examining social platforms, gray areas exist. For instance, professionals who live and practice in small towns or rural settings have difficulty avoiding dual relationships. Additionally, professionals who serve on boards with patients may have difficulty avoiding shared LISTSERVs, blogs, or social networking sites.

Interestingly, though renal professionals face ethical dilemmas related to appropriate use of social media, only 47% of those surveyed said they were certain that social networking policies were addressed at their facilities or practices.

There were less than 100 respondents in the audience. It would be interesting to repeat this polling with a larger and more randomized sample, which would provide the opportunity to explore some cross-tabulations.

Current Events

A survey of the Boards of Nursing conducted by National Council on State Boards of Nursing (NCSBN, 2010) indicated an overwhelming majority, 33 of 46 respondents, reported receiving complaints about nurses who have violated patient privacy by posting photos or information about patients on social networking sites. Disciplinary actions were taken based on these complaints, including censure, letters of concern, conditions placed on the nurse's license, and licensure suspension.

One recent incident was publicized in the media (Stokowski, 2011). Four students were dismissed from their nursing program after a student posted a photo on Facebook showing her posing, smiling widely, over a placenta in a plastic tray, while holding up the umbilical cord in her gloved hand. Although nothing in the photograph identified the patient from whom the placenta was taken, the student was wearing a uniform with a visible decal, as well as a hospital badge on a lanyard that contained identifying information. Although the photo was taken down from her Facebook page, it is still available on the internet, as it was picked up by the press and a host of online bloggers.

In a recent research letter to the *Journal of the American Medical Association* (Hensley, 2012), it was reported that 3% of "Tweets" from self-reported physicians on Twitter were unprofessional. The letter shared results of a nationwide survey of state medical boards, the majority of whom have received reports of doctors behaving badly online. The most common violations reported were: inappropriate patient communication online, e.g., sexual misconduct; use of Internet for inappropriate practice, e.g., prescribing without established clinical relationship; and online misrepresentation of credentials. Most often, the boards have learned about the problem from patients or their families. Fifty-six percent of the boards had restricted or suspended licenses, and have revoked at least one doctor's license at some point for bad behavior online (Greyson, Chretien, Kind, Young, & Gross, 2012).

Results of a survey of medical school administrators (Chreitien, Greyson, Chretien, & Kind, 2009) found a fair amount of unseemly conduct by their students, including violations of patient confidentiality, student use of profanity, frankly discriminatory language, depiction of intoxication, and sexually suggestive material. Among the 78 medical schools that responded to the survey, 60% reported incidents of students posting unprofessional content on the web. Unprofessional online content posted by medical students has resulted in disciplinary action by medical schools, including dismissal in some cases.

Amednews.com reported in April (Dolan, 2012) that patients increasingly want social media to be something that helps them coordinate care and navigate the health system, and they think physicians are the best people to deliver it. Health care organizations are reshaping their social media strategies to engage patients, interact with them, and even provide services in an attempt to help bring down the costs of providing care. Examples include scheduling appointments, sending reminders, and making referrals to specialists. Mercy, a 28-hospital system in the Midwest, is creating an application to allow patients to “share” their physicians’ profiles with Facebook Friends.

Ethical Considerations

When using technology in its various forms, renal professionals need to adhere to ethical, legal, and regulatory standards. The Health Insurance Portability and Accountability Act (HIPPA) (U.S. Department of Health & Human Services, 1996) defines individually identifiable information, and establishes how the information may be used, by whom, and under what circumstances. Individually identifiable information is any information that relates to the past, present, or future physical or mental health of an individual, or that provides enough information that leads someone to believe the information could be used to identify an individual.

In addition to adherence to HIPAA privacy regulations, it is important to review your individual professional organization’s policies on ethical practices in the use of technology. Several professional organizations have updated their policies to address social media. Those that are relevant to renal professional practice are summarized in Figure 1.

Possible Consequences of Violations

Keep in mind that inappropriate disclosures or postings on social media may result in disciplinary actions by professional boards, state and federal entities, and employers. Additionally, individual lawsuits can be filed against professionals and subject employers to lawsuits or regulatory consequences (e.g., defamation, invasion of privacy, or harassment). The reputations of health care organizations are at stake.

Professional boards may investigate reports of inappropriate disclosures on social media on the grounds of: unprofessional conduct, unethical conduct, moral turpitude, mismanagement of patient records, revealing privileged communications, and breach of confidentiality. Consequences may include reprimand or sanction, assessment of monetary fine, and temporary or permanent loss of licensure.

State and federal entities oversee violation of laws established to protect privacy, confidentiality, and prevention of patient abuse or exploitation. Consequences may include civil and criminal penalties, fines, jail time, and personal liability.

Some Recommendations

If you are uncertain, seek consultation on ethical issues. Some of the professional values and personal guidelines to keep in mind when using social media:

- *Conflicts of interest*—Avoid activities that interfere with the exercise of professional discretion and impartial judgment. When posting on professional websites or commenting on a blog, keep it professional, as your comments can be viewed by the public and are archived.
- *Professional boundaries*—“Friend requests” from patients should be respectfully declined *just like any other kind of social invitation from a patient*.
- *Privacy and confidentiality*—Be wary of providing enough information that could be used to identify a patient.
- *Do no harm*—Overexposure on social networking sites may confuse patients and have negative repercussions for patient-staff relationships. Manage information available about you online. Use the highest privacy settings for social networking sites. Create a “lock” on Twitter accounts in order to deny access to requests to follow you. Twitter provides the option to "lock" or protect your account, which means that you must approve people before they can “follow” you and only your “followers” can view your “tweets.”
- *Dignity and respect toward colleagues*—Ask yourself before posting whether the content will be detrimental to your employer or impair working relationships.

SUMMARY

Renal professionals should not shy away from using social media. In fact, social media are more likely to play an increasing role in health care. With thoughtful examination of professional guidelines, creation of agency policies regarding ethics in the use of new media by staff, and discussions with patients regarding policies and procedures, we will be able to participate in the social media revolution without fear of doing harm.

Figure 1. *Professional Organization Policies and Principles*

NASW and ASWB Standards for Technology and Social Work Practice (National Association of Social Workers, 2005)

- Adhere to ethical, legal, and regulatory standards (privacy, confidentiality, client records, informed consent)
- Inform clients when real or potential conflicts of interest arise; take steps to resolve; clients' interests are primary
- Do not engage in dual or multiple relationships with clients or former clients in which there is risk of exploitation or potential harm
- Respect clients' right to privacy; do not solicit private information unless it is essential for providing services
- Do not permit private conduct to interfere with the ability to fulfill professional responsibilities
- Overexposure on social networking sites may confuse clients and may negatively impact the relationship (personal internet postings are a form of self-disclosure)

ANA's Principles for Social Networking and the Nurse: Guidance for the Registered Nurse (American Nurses Association, 2011)

- Negative aspects of social networking sites include: loss of privacy, legal liability, and loss of professionalism
- Crossing personal and professional boundaries can represent conflicts of interest for the nurse
- Protect the integrity of self and profession
- Maintain patient privacy and confidentiality; treat patients with dignity and respect
- Promptly report breaches of confidentiality or privacy
- Do not make disparaging remarks about employers or coworkers

NCSNB White Paper: A Nurse's Guide to the Use of Social Media (National Council of State Boards of Nursing, 2011)

- Avoid inadvertently disclosing confidential or private information about patients (including use of patient information or likeness)
- Maintain professional boundaries online
- Do not disparage employers or coworkers
- Be aware of employer social media policies
- Report any breaches to your state's Board of Nursing (BON)

AMA Policy: Professionalism in the Use of Social Media (American Medical Association, 2012)

- Policy does not explicitly recommend against "Friending" patients
- When interacting online, maintain appropriate boundaries of patient-physician relationship, just as with any other context
- Recommend separating personal and professional content online

ACP Ethics Manual, 6th Edition—A Comprehensive Medical Ethics Resource (American College of Physicians, 2012; Barclay, 2012)

- Physicians who use social media should not blur social and professional boundaries
- Policy provides guidance regarding confidentiality in electronic health records

Academy of Nutrition and Dietetics (2011)

- Development of an ethics opinion is underway, based on the following guiding principles:
    - Do not engage in false or misleading practices or communications
    - Protect confidential information
    - Provide full disclosure about limitations on ability to guarantee full confidentiality
    - Be alert to real or potential conflicts of interest and act when conflict arises

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Dialysis Rationing and the Just Allocation of Resources: An Historical Primer

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Historically, dialysis was a rationed medical resource. Access to treatment was restricted and based on perceived medical suitability and judged social worth of the patient. With the passage of P. L. 92-603, the federal government solved the problem of access by providing dialysis to all in need. However, the federal government avoided the core issue of how to justly allocate a scarce medical resource. Today, Medicare is a major federal government expenditure vulnerable to drastic budget cuts. Given the current political climate concerning the reduction of Medicare, the purpose of this paper is to examine the early allocation of kidney dialysis, discuss the federal government's policy reaction at that time, and begin a discussion regarding the implications of the just allocation of dialysis in the event of health care rationing.

INTRODUCTION

End-stage renal disease (ESRD) is a chronic illness that currently affects 571,000 people in the United States (USRDS, 2011). In 2009, 370,274 patients were using hemodialysis as an ESRD treatment regimen (USRDS, 2011). Since 1972, most patients diagnosed with ESRD are eligible for Medicare to cover the costs of dialysis.

Prior to federal government intervention in 1972, hemodialysis was viewed as experimental and funded primarily through donations and the private funds of patients (Browne, 2012; Peitzman, 2001). There were many more ESRD patients needing treatment than available dialysis machines or funds to pay for treatment expenses. As a result, dialysis was rationed. Rationing is the allocation of a needed, yet scarce, resource (Jonsen & Edwards, 2010). The end result of rationing is that some people receive the resource and others do not. In the case of dialysis, treatment was allocated based on medical suitability and perceived social worth of the patient. The use of social worth criteria for rationing dialysis in the early years is criticized as being unfair, unequal, and unjust. The rationing of dialysis during this time was not allocated in a just manner, resulting in an unfair distribution of resources (Emanuel, 2000).

There was a public outcry based on the inherent injustice of dialysis allocation, and the federal government responded with Public Law (P. L.) 92-603 in 1972. P. L. 92-603 established the U.S. ESRD program, mandating Medicare coverage for dialysis patients, regardless of age or ability to pay (Browne, 2012). End-stage renal disease patients, their families, nephrologists, and the American public vigorously supported the passage of Public Law 92-603. The federal government avoided the ethical question of who was to receive an expensive, scarce resource, and instead provided the resource to everyone who needed it with the passage of the law. The government determined that kidney disease was different from other chronic diseases and deserved full monetary coverage by taxpayers. In addition, given cost predictions, it appeared in 1972 that the cost of treatment for ESRD patients could be covered by taxpayers well into the future.

According to Puckrein and Norris (2007), the congressional debate concerning the cost of the U.S. ESRD program began soon after the passage of the 1972 law. The cost predictions proved inadequate, and the number of people in need of dialysis increased dramatically. During the congressional debate regarding the proposed law, the National Kidney Foundation projected that costs for the first year of the ESRD program would range from $35 to $75 million (Blagg, 2007). However, the actual cost for the first year of the program was $241 million (Rubin, 1984). Also, nephrology experts thought that the population of ESRD patients would increase from 5,000 to 7,000 upon implementation of the ESRD program. However, the number of ESRD patients totaled 10,300 in the first year of the program (Rubin, 1984). In addition, Senator Hartke (D-IN), a supporter of the bill, estimated that costs of the ESRD program would decrease over time as technological advances occurred. He argued that these advances would lead to cheaper methods of dialysis and transplantation (Blagg, 2007). This has not transpired.

Currently, health care is a primary political and budgetary concern. Much political debate has ensued regarding the amount of the national budget allocated to Medicare. Some politicians are calling for large budgetary cuts in Medicare, as well as other government programs that aid Americans in covering their health care costs. Such conversations create the following questions: What if funding for the ESRD program was significantly reduced? What if dialysis were once again a scarce and rationed resource? How could dialysis be justly allocated?

The purpose of this paper is to use the theory of distributive justice to examine the early allocation of kidney dialysis and discuss the federal government's policy at that time. In addition, given the current political climate concerning the reduction of federal government health care expenditures, the purpose of this paper is to begin a conversation regarding the implications of a just allocation of dialysis in the event of health care rationing.

THEORY OF DISTRIBUTIVE JUSTICE

According to Roemer (1996), the theory of distributive justice is the determination of how scarce resources are allocated among members of a society or group when such members have competing interests. Therefore, distributive justice involves the just allocation of resources. Distributive justice has evolved from the Aristotelian notion that scarce resources should be allocated based on individual merit to the modern notion that all members of society should be guaranteed a "certain level" of resources (Roemer, 1996, p. 4). The crux of the modern ethical debate is how to define a "certain level."

In the area of health care, the just distribution or allocation of resources is particularly pertinent given the current economic condition of the U.S. With attempts to contain health care expenditures, attempts may also be made to limit health care resources to those most in need. If health care resources become scarce, how can they be allocated in a just fashion?

SOCIAL WORK ETHICAL CONSIDERATIONS

The theory of distributive justice is a potential guide to decisions regarding the allocation of scarce medical resources. As social workers, we are also guided by our professional ethical values and principles. Ethical values, such as social justice and respecting the dignity and worth of a person, are integral to any resource allocation decisions that we make (NASW, 2008). Further, the NASW Code of Ethics that guides social work practice is clear that social workers must practice within its principles when addressing social problems and challenging social injustice.

Social justice is defined as the condition where citizens receive equal benefits and burdens in a society (Barker, 1999). Social workers are ethically mandated to advocate for clients to ensure that they receive an equal share of benefits. Therefore, social workers must advocate for vulnerable clients when they are denied access to or are in danger of losing access to scarce medical resources.

Respecting the dignity and worth of a person means that social workers hold their clients in high esteem, honor their personal story, and respect their uniqueness (Saleebey, 1997). Social workers also work with clients to ensure that they are treated fairly and respectfully in the broader society. Therefore, when health care resources are scarce, social workers work to ensure that clients receive the resources to which they are entitled and that they require.

MEDICAL ETHICAL CONSIDERATIONS

In addition to social work ethical considerations, there are also medical and ethical considerations. In their article, *Principles for Allocation of Scarce Medical Interventions* (2009), Persad, Wertheimer, and Emanuel outline core ethical values that can be applied to the just allocation of resources. The first ethical value is treating people equally. According to the authors, treating people equally involves ensuring that each person has an equal chance at medical services (Persad, Wertheimer, & Emanuel, 2009). The second ethical value considered in a just allocation of resources is favoring the worst-off. Those considered the worst-off are those who are presently or throughout their lives bereft of "valuable goods" (Persad, Wertheimer, & Emanuel, 2009, p. 424). The third value is maximizing total benefits, which can be achieved through maximizing the number of lives saved, the number of years of life saved, or the adjusted years of life saved (CDC, 2011; Persad, Wertheimer, & Emanuel, 2009).

HISTORY OF EARLY ALLOCATION OF KIDNEY DIALYSIS

In 1943, Willem Kolff invented the first artificial kidney (Friedman, 1998). The artificial kidney unit was expensive to produce and maintain; thus, few were created. The artificial kidney required physical access to the circulatory systems of patients. Patients were surgically connected to the artificial kidney. Surgical connections were only feasible for short-term use due to the possibility of surgical wound infections. Given these constraints, Kolff and the medical community envisioned the artificial kidney as only useful for patients suffering from acute renal failure who would recover with a few treatment sessions (Friedman, 1998). Patients suffering from chronic kidney failure were not considered appropriate candidates for treatment. Therefore, allocation decisions were based on medical diagnosis (Friedman, 1998).

In the 1950s, allocation expanded to include some patients with chronic kidney disease. By this time, pharmaceutical companies had begun manufacturing and offering more affordable artificial kidney units. Kolff and his colleagues offered treatment to chronic kidney disease patients only if their present physical deterioration was caused by something other than the chronicity of their disease, such as surgery or acute infection (Peitzman, 2001). Therefore, the medically appropriate criteria expanded. However, no codified medical standards of care existed. Doctors were left to make individual decisions as situations arose, with little guidance from the medical community.

In 1960, Scribner revolutionized kidney dialysis with his invention of the dialysis shunt (Peitzman, 2001). The shunt was a device surgically inserted under the skin of the forearm, which allowed constant access to patients' circulatory systems. This technological advance meant that dialysis could be offered to patients with chronic kidney disease on an outpatient basis. However, dialysis was still quite expensive. In the early 1960s, the cost of dialysis was $15,000 per person per year (Fetherstonhaugh, 2009). Scribner obtained funding from the Hartford Foundation and began offering community dialysis through the Seattle Artificial Kidney Center (SAKC) in 1962 (Peitzman, 2001).

Throughout the 1960s, several community dialysis centers began operation, but little is written about them. The SAKC was the exception, with its history being well documented. Upon opening, the SAKC was inundated with chronic kidney disease patients in need of dialysis. In the early 1960s, it was estimated that 40,000 people were dying a year from ESRD (Fetherstonhaugh, 2009). To choose who would receive dialysis, Scribner and his colleagues devised a two-tiered patient selection system. The first tier of the selection process was based on the following criteria: patients had to be stable, emotionally mature, uremic adults under the age of 45, without long-standing hypertension and vascular complications, willing to cooperate with the dialysis and low protein/low sodium dietary regimens, and with stable or slowly deteriorating renal function (Blagg, 2007, p. 485).

The medical criteria also included a psychological assessment to ascertain if the patients had the ability to "…take an active role in their own well-being; have the potential for rehabilitation" (Fetherstonhaugh, 2009, p. 89). Rehabilitation was defined by the doctors as having the potential to be a productive citizen and live a "useful life" (Fetherstonhaugh, 2009, p. 89). Furthermore, young adults who could not financially support themselves were rejected. Children were not considered candidates for dialysis for two reasons. First, the procedure presented too many complications with children, and Scribner and his colleagues wanted those patients with the best chances of survival to receive dialysis (Blagg, 2007). Second, those at SAKC making the selection decisions thought it unfair to allow a child to receive dialysis and deny dialysis to a patient who was the head of a household consisting of many children (McGough, Reynolds, Quinn, & Zenilman, 2005).

The second tier of the selection process involved the Admissions and Policies Committee. This was an anonymous committee comprised of seven community members that included a "…lawyer, a minister, a banker, a housewife, an official of state government, a labor leader, and a surgeon" (Alexander, 1962, p. 107). The committee members were also described as being white, Protestant, middle-class citizens (McGough et al., 2005). The task of the committee was to make final patient selection decisions. The committee based their decisions on many factors, including level of education, marital status, net worth of patients, work performance and history, and number of dependents. The committee selected patients who they thought had the most potential to remain, or become, productive community members. The determining factor was how important the committee thought each applicant was to the community. In other words, they used social worth as their standard of measure.

For the committee members, social worth was narrowly defined by their own backgrounds and value systems. This was evidenced by the patients whom they chose to receive dialysis. The committee overwhelmingly chose men who were white, middle class, married fathers with many children, who were active in church and the community, and who had a history of positive performance at work (Blagg, 2007; Fetherstonhaugh, 2009; McGough et al., 2005). It is important to keep in mind that those they did not choose, those who did not correspond to these values, died.

Months after the SAKC began providing outpatient dialysis, Shana Alexander (1962) wrote an article for *Life* magazine (Blagg, 2007). In it, she described SAKC's mechanism for dialysis allocation. The public was appalled that patients were selected to live because of their apparent usefulness to society (Blagg, 2007). Interestingly, the medical criteria, although scrutinized today, was considered at inception to be value-free and without bias. Therefore, the focus of public outrage and resulting ethical conversations centered on the injustice of using social worth as a criteria for dialysis rationing.

THE REACTION OF THE FEDERAL GOVERNMENT

According to Blagg (2007), the federal government's reaction to this outrage was threefold. First, the federal government gave grants to SAKC and a Brooklyn community dialysis center in 1963. Second, dialysis units were established in 30 Veterans Administration hospitals. Third, the Committee on Chronic Kidney Disease, headed by Dr. Carl W. Gottschalk, was established in 1966 to advise the federal government on how to proceed with efforts concerning kidney dialysis and transplantation. The Gottschalk Committee reported that dialysis was no longer experimental but a viable, life-sustaining treatment for patients with chronic kidney disease, and that it should be funded by the federal government through the Medicare program (Blagg, 2007). By 1968, however, the nation was embroiled in the Vietnam War, and the report received little notice. In addition, the SAKC dissolved the Admissions and Policies Committee, but it continued to select patients for dialysis based on social worth, even though the center was receiving federal grant monies (McGough et al., 2005).

In 1971, the Nixon administration introduced the idea of a national health care plan. During the congressional debates concerning the feasibility of a national health care plan, the Gottschalk Committee report was released again, and kidney dialysis was once again part of the national consciousness (Blagg, 2007). Various congressional members, who had friends who were on dialysis, championed Medicare funding for dialysis. The Ways and Means Committee began hearings to explore the issue further. Patients and family members from the National Association of Patients on Hemodialysis (NAPH) and nephrologists spoke during the committee hearings. At one point during the hearings, the vice president of NAPH dialyzed before the committee members (Blagg, 2007).

The Ways and Means Committee dialysis hearings were reported widely by the press, and the bill amending the Medicare program was introduced to Congress. The bill was passed by both the House and Senate with little debate. On October 30, 1972, President Nixon signed the bill establishing the ESRD Medicare program (Blagg, 2007). The ESRD Medicare program avoided the ethical dilemma of how to fairly allocate dialysis to ESRD patients by funding the dialysis of all ESRD patients. Therefore, no ESRD patient would be denied dialysis based on inability to pay for services. All rationing ended when the bill became law in 1972.

JUST ALLOCATION OF RESOURCES

Since the passage of P. L. 92-603, the federal government has subsidized the vast majority of kidney dialysis in the United States (SSA, 1972). Medicaid, private insurers, and state kidney health programs also contribute to dialysis reimbursement; however, the principal responsibility of reimbursement falls on Medicare. In 2009, Medicare paid 83% of medical costs for the ESRD population (USRDS, 2011). The cost of ESRD rose 3.1% in 2009 and comprised 5.9% of the total Medicare budget, totaling $42.5 billion (USRDS, 2011).

In addition, the population in need of dialysis services is increasing. There was a 2.1% increase in those diagnosed with ESRD in 2009, and a 3.2% increase from 2008 to 2009 of those enrolled in the Medicare ESRD program (USRDS, 2011). Also, the cost for ESRD increased 3 to 4% per person in 2009 (USRDS, 2011).

There has been a political debate regarding the rising costs of health care and the federal responsibility for health care costs. In the annual summary report concerning the status of Social Security and Medicare, Geithner et al. (2011) reported that Medicare reserves for hospitalization insurance would be depleted in 2025, and the reserves for outpatient and pharmaceutical costs are diminishing. Geithner et al. (2011) also cited an increase in the number of aging U.S. citizens and a continual rise in health care costs as the chief reasons for the depletion of Medicare. Reducing government health care expenditures means reducing Medicare expenditures since Medicare is a large federal health care program. In addition, since Medicare is the primary payer for ESRD patients, it is quite possible that budget cuts would profoundly impact the ESRD community.

The final rule of the Centers for Medicare and Medicaid Services (CMS) restricting Medicare reimbursement to dialysis centers was enacted in January 2011 (Centers for Medicare and Medicaid Services, 2010). The rule complies with P. L. 110–275 of 2008, which is the Medicare Improvements for Patients and Providers Act (MIPPA, 2008). The final rule of CMS increases the amount of money that some patients will have to pay toward their dialysis medications and dialysis laboratory tests (Centers for Medicare and Medicaid Services, 2010). Puckrein and Norris (2007) argue that some of the cost-cutting strategies concerning ESRD patients may include limiting provider choices and restructuring ESRD physician reimbursement systems. They also maintain that ESRD services may once again be rationed through stricter eligibility criteria, leading to exclusions of vulnerable populations, such as poor people of color (Puckrein & Norris, 2007). Rationing would involve a decrease in the budgetary allotment for Medicare, affecting the ESRD program on the macro level. Less money for the program would result in reduced life-sustaining services for ESRD patients on the micro level. How these services are distributed or rationed, once it is determined that the present ESRD program is not monetarily sustainable by the taxpayers, is the crux of a potential ethical dilemma in health policy.

The political debate concerning health care budget reductions has potential consequences for the ESRD population that may affect their quality of services, eligibility for services, and types of services available; in effect, services may be rationed. These are not simply health care expenditure issues but allocation of resource issues. Therefore, the consequences of the political decisions have deep ethical ramifications. How can ESRD resources be justly allocated if dialysis were once again rationed?

Rationing often occurs in the United States. Hospitals, organ donation organizations, and government agencies routinely devise rationing criteria for scarce resources. Choices are made concerning who receives the last bed in the intensive care unit or the available organ when there are several people who are in need. Vaccines, influenza drugs, and antiretroviral drugs are given to some and withheld from others. However, the rationing criteria are generally referred to as distribution criteria or eligibility criteria. In addition, as the demand for scarce resources increases, hospitals, organ donation organizations, and government agencies meet this new obstacle by devising stricter eligibility requirements. In other words, the rationing criteria become less inclusive even as these entities try to meet the need for fairness or just allocation.

In Seattle, the ESRD community was subjected to unfair resource allocation prior to the Medicare ESRD program. The criteria used to allocate the scarce resource, dialysis, were based on the social worth of the individual. Ethicists resoundingly agree that social worth is not a fair criterion for allocation of resources (American Medical Association's Council on Ethical and Judicial Affairs, 1995; Beauchamp & Childress, 2009; Gillion, 1985; McKneally, Dickens, Meslin, & Singer, 1997). If not social worth, then what should the criteria be?

Unfortunately, there are no concrete rules for the just allocation of resources. In addition, it appears that all criteria are subject to manipulation and distortion. Jonsen and Edwards (2010) note that the SAKC attempted to ration dialysis in a fair manner during their first-tier selection by using the criteria of "likelihood of medical benefit" (p. 2). However, even this apparent value-free medical concept of benefit is not actually free of bias. Persad, Wertheimer, and Emanuel (2009) argue that all decisions about medical need are really value-based judgments. They maintain that doctors and medical staff are not free from acquired cultural and societal values; therefore, all of their decisions are value-laden. Although the SAKC is not often criticized for its practice of rationing based on potential medical benefit, this criterion is not a completely fair and just means of resource allocation.

CONCLUSION

The prospect of rationing dialysis is an unwelcome one. However, as mentioned before, health care has and will continue to ration care as available resources dictate. Many different models of rationing have been implemented and even more proposed. Availability and cost are generally the two drivers of such rationing. Anticipated technological advances have not delivered the hoped-for decrease in dialysis costs. Instead, the cost of dialysis and the need for dialysis continues to escalate.

After 40 years of dialysis coverage, some patients are now being asked to pay a higher share of the dialysis burden. Given our nation's current fiscal plight, dialysis rationing does not seem so preposterous. How, then, to do it to the satisfaction of all? Or, failing that (as seems most likely), what improved model should replace the social worth criteria of the 1960s?

Any acceptable rationing model would need to be cognizant of the influences of values, norms, and culture in forming rationing decisions. The model must eliminate (as much as possible) extraneous criteria that are not relevant, and it must involve the stakeholders. In addition, it must make the process as transparent as possible.

The three ethical values involved in just allocation of resources—treating people equally, favoring the worst-off, and maximizing total benefit—must be incorporated to every extent possible into this model. Paradoxically, these values can oppose each other as the complete satisfaction of or use of any one value exclusively will violate the tenants of the other two. For example, using a lottery system (treating people equally) will not favor the worst-off or maximize total benefits.

Any system that takes these values into account will satisfy no one value completely. Instead, as with most human systems and endeavors, compromises will have to be made. The discussion of those compromises should start now so the nation is prepared should rationing prove necessary. As social workers dedicated to working with patients with ESRD, we must address the issue of just allocation of dialysis and life-sustaining medications before a crisis erupts. The fiscal constraints imposed by the federal government on the ESRD program appear to be persistent and ever-deepening. Therefore, social workers have a unique opportunity to begin the conversation concerning just allocation of dialysis for the sake of our current and future ESRD clients.

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Nancy Spaeth's Story: A Little History and a Lot of Hope

Lisa Hall, MSSW, LICSW, Northwest Renal Network

The preceding historical primer by Savage and Browne documented that access to hemodialysis in the U.S. was not always available. Life-and-death decision making that occurred in Seattle no doubt affected individuals and families dramatically as the following interview illustrates. Lisa Hall, MSSW, LICSW, is the Patient Services Director at Northwest Renal Network (ESRD Network 16). Nancy Spaeth serves on the network's Patient Advisory Committee.

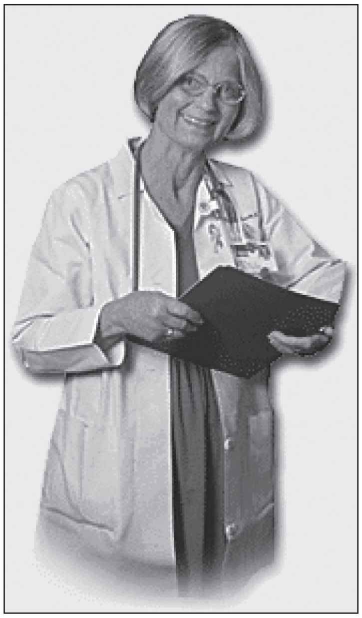

Figure 1. Nancy Spaeth – Editor and "mascot" for Kidney School, a program of the Medical Education Institute, Inc.

Nancy Spaeth is a registered nurse and has been living with kidney disease since 1959. I first met Nancy two years ago, when I moved to the Pacific Northwest. Right away, I realized that she was someone I would admire, even if she had not lived most of her life with chronic kidney disease. When I was asked by *JNSW* to interview Nancy, I considered it an honor, and an opportunity to learn more about this inspiring woman and all she has accomplished. Nancy exemplifies the strength of the human spirit and its ability to triumph over life's obstacles. She brings thoughtfulness, intelligence, wisdom, and enormous energy to all she does. Nancy is a highly effective advocate on patient, legislative, and administrative fronts for improvement in care and enhancement of personal autonomy, offering the rare dual perspective of both patient and expert caregiver in all her activities. Readers may recognize Nancy's photograph—for over a decade she was the "face" of Kidney School. Her photograph was featured on Life Options posters and brochures, and the Kidney School website modules. The following are excerpts from an interview conducted in June 2012.

Hall: Tell me about the early days of your diagnosis with chronic kidney disease.

Spaeth: I had just started 7th grade in September 1959 when brushing my thick, wavy blonde hair became difficult. I was a relay runner in school and races became hard to run. My urine became brown. The diagnosis was kidney disease. In that era, the doctors thought that jostling the kidneys would do further harm, so I was sent to bed until Christmas and only arose to use the bathroom.

In October, my friends gathered around my bed to celebrate my 12th birthday. It was one of those rare times I saw all of my friends, as I was usually alone in the house while my mother was at work. I did my best to keep busy by reading Charles Dickens, Jules Verne, and the Nancy Drew mysteries.

On December 26, I entered the Children's Hospital in Seattle for further diagnostic tests and treatment if needed. A biopsy showed that I had Bright's disease or glomerulonephritis, as it is called now. The doctors felt the cause was multiple stings from a swarm of yellow jackets I had encountered the previous summer while on a camp hike in the Cascade Mountains. I was there [at Children's Hospital] for many weeks and given high doses of prednisone, and then infused with nitrogen mustard to see if it would eradicate the disease. I was semiconscious for several days following this. Eventually, I was awake enough to ask my mother to hold open my swollen eyes so that I could see her. Children's visitors were not allowed in the hospital in those days, and I remember waving at my younger brother, Charlie, through the windows of the hospital.

I entered the 8th grade the following autumn and stayed active throughout my junior and senior years in high school. I loved water skiing in the summers on my custom made slalom ski. At the age of 15, I won a first-place trophy snow skiing in a coed slalom race. As a girl competing with brothers while growing up, I never tired of saying, "I beat the boys." Back then, I never worried or thought much about my illness, except to be careful of my diet and to follow the doctor's instructions. I always knew I felt better when I watched my salt intake. This was just my life.

In the fall of 1965, I went off to college at the University of Arizona in Tucson, joined the Phi Beta Phi sorority, worked at my studies, went to parties, and dated. By February1966, I had become too sick to stay in school. Vomiting in the planter boxes outside of my physics class became old after a while. I returned home and continued college at the

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University of Washington, and then transferred to Seattle University, which was just three blocks from the Seattle Artificial Kidney Center. I also began my interviews with the Admissions and Policy Committee at the center. We called it "The Life and Death Committee." All patients being reviewed for dialysis in Seattle, in those days before Medicare paid for treatments, went through this process. It included a visit with a psychiatrist and psychological testing. My mother and older brothers had to meet with the social worker and the financial people. However, I did not know until recently that my family had to have adequate insurance coverage or put up $30,000. That is a lot of money, even by today's standards. Luckily, my mom was a social worker for the state of Washington and had excellent insurance.

The committee was looking for people who could recover and go on to work or be "contributing members of society." The Seattle Artificial Kidney Center was the first out-of-hospital dialysis center in the world and it only had about two dozen dialysis beds. I believe the review process was harder on my family than it was on me, because they worried about the alternative. My sister-in-law reminded me that I might not be chosen, but I was 18 and the implication of death never really occurred to me.

Hall: What was dialysis like in 1966?

Spaeth: I started dialysis the day after Christmas 1966, while continuing to be a full-time university student. I was active, went to parties with my friends, dated, and was a pretty normal student, except that I went on dialysis at bedtime three nights a week for eight hours and avoided salt at all costs. I took up snow skiing again, although I carried a tourniquet and cannula clamps with me on the hill. I had a Scribner shunt, an external Teflon and Silastic tube connecting an artery and a vein, located on my inner forearm where it was vulnerable to infection, clotting, and being pulled out. I covered it with gauze to keep it warm and protected. We allowed the end junction to show, in order to keep an eye on the blood color and check for clotting. I often volunteered for research studies, thinking that anything the doctors learned would benefit me as well as others. I was planning for the future—my future. In 1968, after over two years of in-center dialysis, and while still in college, I went to home dialysis training at The Coach House, where the University of Washington conducted research. I was taught to be a nurse and technician. Dr. Belding Scribner, accompanied by Dr. Joseph Eschbach and Dr. Christopher Blagg, was there to oversee my health and training. It took three months for me to learn how to dialyze, [how to] repair the Drake-Willock machine, and how to rebuild the Kiil dialyzer, which I would be using in my home. (Information on this historical technology is available at **http://homedialysis.org/index.php/types/museum/P5**.) [At home] we prepared a room in our basement with an old hospital bed for sleeping during overnight dialysis. On Sundays, my priority was to clean and rebuild the kidney. Dialyzers today come ready to use, a big advance for patients. Mom and I eventually gave free room and board to a university student in exchange for help with the machine. My hematocrit hovered around 20 to 23 in those days, and I had frequent blood transfusions. I still went on dates, but had to be home at night in time for dialysis.

In June 1970, I graduated from Seattle University with a Bachelor of Education degree with minors in Art and English.

Hall: How does your early dialysis experience compare with treatment for kidney disease today?

Spaeth: Frankly, my dialysis was better [back then] because I dialyzed overnight, and did not have to give up my days. In the 1980s, when I lost my kidney transplant and went back in center for dialysis, I had to dialyze three days a week for four hours each visit. Nobody could prescribe anything else at that time. I felt much worse on that schedule. I was anemic, my hematocrit ran from 11 to 15, and EPO was not available yet. They weren't performing blood transfusions as frequently, due to concerns about building up antigens that might preclude another transplant, and getting infectious diseases (Hepatitis C and HIV).

If I were to go on dialysis again, I would definitely choose to do daily home nocturnal dialysis, or possibly CAPD.

Hall: Can you provide a summary of the various treatment modalities you've had over the years?

Spaeth: In March 1972, during my youngest brother Charlie's spring break from college, he gave me his kidney after I had dialyzed from 1966 to 1972. He returned to school at Stanford a week later. That summer, I married. My first child, Joshua was born in February 1974. My daughter Sarah was born in August 1976. They were beautiful, healthy babies, though born four and three weeks early. They are still beautiful and healthy today. After Sarah was born, I was a substitute teacher and taught kindergarten through 12th grade, all subjects.

In 1979, I lost my transplant due to food poisoning, and was divorced. Public schools were closing, and many teachers were out of work. I was unable to get a teaching job, so I returned to school for a nursing degree, and dialyzed at what was now called the Northwest Kidney Center. The center was using a new, more efficient type of dialyzer that physicians thought would permit a shorter treatment schedule. I remember telling Dr. Scribner that I did not feel as well using this new machine on a four hour dialysis schedule. I also disliked taking time out of my day for treatments. I had preferred sleeping away my time during overnight dialysis, so that I would have my days free for school, work, and my children.

Fortunately, I soon received training for home hemodialysis. I liked managing my own life and not letting dialysis manage me. This time, the machine was small enough to keep in the kitchen where I could interact with my children and supervise dinner. My hematocrit hung at around 15. I was getting fewer transfusions now, as a protection against HIV infection and accumulating antigens, in the hope that a low hematocrit would stimulate production of red blood cells. For that purpose, I also received the male hormone, decadurobolin. Nothing seemed to work.

In 1981, I received a cadaveric transplant from a young woman who fell from a ladder on a fishing barge in Alaska. The following year I graduated from nursing school with a 3.9 GPA and went to work full time. When my transplant failed in 1986, I once again went on dialysis, for the standard four-hour day. My hematocrit again dropped to 15, and I felt quite tired from the anemia—more so than in the past. I soon opted for home hemodialysis, again in the kitchen. This time, however, the kitchen was in the [new] house that I had built (acting as my own contractor). Still, the four-hour schedule was not enough to help me feel as well as I did on overnight dialysis during the 1960s and early 1970s. Unfortunately, nephrologists no longer prescribed that type of overnight schedule. [*Editor's note:* In recent years, access to longer and overnight dialysis has begun to become available again as the medical community has recognized the benefits.]

Not long after, I was accepted into the erythropoietin study conducted by Dr. Joseph Eschbach at the Northwest Kidney Center, and my hematocrit climbed to 40! I could walk up stairs again, rather than having to crawl. My daughter Sarah, no longer needed to keep coming into my room while I was napping to make sure Mommy was okay. It is a frightening thing to have a sick Mommy. The Food and Drug Administration eventually approved Epogen (EPO) in 1989. Patients today have little knowledge of just how lucky they are to have this drug. It was unbelievable how much better I felt. With EPO, I was able to spend more active time with my children, but because of that terrible four-hour dialysis schedule, I still never felt well enough to work full time.

"I liked managing my own life and not letting dialysis manage me."

In 1989, I received my third transplant, again a cadaveric kidney, this time [from a person who was in] a motorcycle accident. I continued to substitute teach and do per diem nursing. For fun, I even tried a spin around Lake Washington on water skis. I made sure that my children learned to snow ski; I know that my son Josh has been grateful. I returned to full-time nursing in 1993. It was great to bring in a good paycheck again and have better medical coverage for doctor visits and medications.

In 1995, I lost my transplant due to chronic rejection and returned, again, to dialysis. As terrible as it is to lose a transplant, I feel that trading off the side effects of dialysis for the side effects of the transplant drugs and vice versa, has contributed to my longevity. I continued to work in the clinic during this period and only took time off for the placement of a Tenckhoff peritoneal catheter so I could start continuous ambulatory peritoneal dialysis (CAPD). The only accommodation I needed was an IV pole at home and in my office so that I could do an exchange while at work, and a microwave oven to warm the dialysate fluid to body temperature. I did four exchanges of fluid a day and was amazed at how much better I liked PD than hemodialysis. I had much more freedom, more consistency in the way I felt, and no more post-dialysis fatigue. It was easy to travel, and my diet was much more normal. I did not lose weight and actually gained some! After one year, I increased to five exchanges a day. The Quantum machine did the fifth exchange at night while I slept. A timer on the machine automatically opened and closed the dialysis tubing.

In June 2000, I received that awaited call—another kidney had been found, a four-antigen match. Sarah stayed by my side until I recovered. She took me to my appointments, arranged for extra help, and cried when Dr. Cooper told us that part of the new kidney had necrosed, explaining to her that it meant that a portion had died. Today, my kidney is working well and I feel healthy. During a hike in the Wasatch Mountains of Utah, I only had to stop once to catch my breath and reminded my hiking companion that I live at sea level.

Hall: Did you ever struggle with depression?

Spaeth: Never. Though I was living with a chronic disease, I realized that everyone has a burden of their own. It is easy to mistake fatigue, listlessness, and a lack of interest for depression but these are symptoms of how one feels with anemia and poor dialysis.

Hall: What is your experience with managing pain?

Spaeth: Having restless leg syndrome was hard, but it eventually cleared up. When I received my bilateral nephrectomy, I was given nothing for the pain. Sure it hurt, but I have always been able to accept the pain as part of it. Getting up and [being] active helps pain, slowly of course, building up over time.

Hall: Where did you seek support for coping with kidney disease?

Spaeth: My family was always there for me, but they never babied me. I guess you could say we were interdependent. Even as a youth, when I lived with my oldest brother and his wife, I was given chores and baby sat my nephews. My mother provided a stoic example of sticking with something until it was finished. My father always said to me, "Nancy, you can do anything if you want it badly enough."

Hall: Is there a particular social worker who helped you with your adjustment to illness?

Spaeth: In the 1960s and 70s, Eloise Jensen was my social worker. Our families were connected and she was a great support and friend to me. Mary Mason, who is now a living donor and a social worker at Virginia Mason Medical Center, was my dialysis social worker and later my transplant social worker. She inspired me, encouraged me, and treated me like a person—not a patient.

Hall: What advice would you give to patients for having a good quality of life with kidney disease?

Spaeth: The way to keep doing the things you love is to keep doing them. Life is a classroom, an adventure. You need to find something to work toward, to hope for. I am hoping for a PhD in "Wisdom." I learn a little bit more every day.

Throughout my adulthood, I have continued to work, support my children, travel, and enjoy life and my family. I garden, walk the dog, climb stairs instead of using the elevator, and still enjoy skiing. I have learned over time how important it is to stay physically active, to maintain a good diet, take phosphate binders, and to maintain a positive attitude. During the day, I still do stretches and exercises [that were] taught to me by my physical therapist while I was on dialysis. They have served me well and kept me strong. Above my desk and on my refrigerator, I have a picture of a pelican eating a frog that is squeezing the bird's neck. The caption says: "Don't ever give up."

> **"I am hoping for a PhD in 'Wisdom.' I learn a little bit more every day."**

Maintaining good nutrition has been a lifelong habit of mine. My mother prepared food without salt when I was a youth. I rarely needed antihypertensive medications, except during pre-dialysis, because I am faithful to the low-sodium diet, staying lower than 1000 mg per day.

As I mentioned earlier, from the start of dialysis in the U.S. in 1960, a "Life and Death Committee" met to determine who would receive this costly medical treatment. By 1962, the committee decided to employ a vocational guidance counselor, to be certain to select dialysis patients who could be rehabilitated to be "productive members of society." In 1972, a national ESRD Program was created to extend Medicare benefits to cover the high cost of medical care for most individuals with ESRD. Returning patients to their prior level of functioning is the reason Medicare began to pay for dialysis. Dr. Belding Scribner testified to Congress at the time that, unless a patient was rehabilitated, the treatment was inadequate. He emphasized that most patients who received funding would be on home dialysis or transplanted, and would be taxpayers. We actually had a vocational counselor at the kidney center where I received dialysis, and I received assistance with my education and career, first as a schoolteacher, and later as a nurse.

Coverage under my mother's health insurance ended when I turned 22 and graduated from college, so I had to get a job with insurance to pay for dialysis. Remember, I was on dialysis way before Medicare covered ESRD. I retired from my nursing career in 2011, but still substitute teach all grades (including kindergartners!) and nurse per diem in pediatrics.

Hall: What advice do you have for social workers on ways to facilitate treatment adherence?

Spaeth: You have to start where the patient is, and instill confidence in them. Let them know you believe in their ability to make changes, and support their efforts. Start with small goals that are important to the patient, and challenge them to try new things.

Hall: Tell me about your contributions to renal-related education and advocacy.

Spaeth: I worked as a member of the Life Options Rehabilitation Advisory Council (LORAC), a group that supports education and rehabilitation for dialysis patients. In addition to LORAC, I have served on numerous boards over the years, including: the Northwest Renal Network (Network 16) Board of Directors and Patient Advisory Committee; the American Kidney Fund Education Committee; and the Northwest Kidney Center's Foundation Board, Quality Committee, and Regional Councils. I also serve on the board for Western Washington Physicians for a National Health Program, and am an elected Precinct Committee Officer. In 2003, I received the Clyde Shields Distinguished Service Award from the Northwest Kidney Centers.

I speak at regional and national renal community meetings about having a good life with kidney disease. I enjoy educating patients and renal professionals about the history of dialysis and rehabilitation for dialysis patients. I'm most passionate about the importance of patients improving their quality of life, whether through home treatment options, transplantation, vocational rehabilitation, and/or physical therapy. I meet with all of the renal fellows who come through the University of Washington and Northwest Kidney Center's programs, and have done so since 2000. I was honored to talk recently with the renal fellows at Seattle Children's Hospital as well.

Additionally, I have advocated in Congress to get kidney disease laws changed, and testified regarding anemia and ESAs. A paper of mine was published in the *Oxford Journal* in 2007 entitled, "Nurse, Mother of Two and Four Transplants — Nancy Spaeth Tells Her Story." I was invited to write a chapter on sodium for the soon-to-be-published book, *Dialysis, History, Development and Promise.*

Hall: What do you see as important new developments in ESRD technology?

Spaeth: I want to see patients get better, longer dialysis, which will increase their quality of life, allow them to be more active physically [and] socially, and in the work force. We can do so much more to rehabilitate people with CKD, as Dr. Belding Scribner promoted. I am also excited that there are new programs available to help donor/recipient pairs with blood types that are otherwise incompatible find suitable donor [pairs]. I think we can do a better job of reaching out to the community regarding living donation to reduce the wait time for kidney transplants. I am hopeful that we will find a way for kidney transplants to last without medications. In the meantime, we have to continue to advocate for Congress to eliminate the 36-month Medicare limit on Part B immunosuppressant coverage.

Hall: Is there anything else you would like to share with *JNSW* readers?

Spaeth: I never really liked the term “Life and Death Committee.” I always considered it a “Life Committee.” They chose [for] me to live—and with that privilege there was a responsibility to realize my full potential. I also prefer chronic kidney disease (CKD) over ESRD and wish that could be changed. I am thrilled that I had the means to help my children with college, and I am quite amazed and feel blessed to have lived to hold my grandchildren. All I ever wanted was a normal, decent life with children and the opportunity to give back to society at least as much as I have been given. I continue to strive toward that end.

Transition From Pediatric to Adult Renal Care: Education, Preparation, and Collaboration for Successful Patient Outcomes

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The transition of patients from pediatric to adult renal care is a complex process that requires careful planning and thorough execution. While the topic is popular and yields much discussion, the recommendations for best practice methods are not well defined. It is clear, however, that the published literature recognizes the importance of a successful transition program leading up to the transfer of care for adolescent/young adult patients. In response to the need for a defined transition program, the dialysis and kidney transplant program at Children's Mercy Hospital developed a transition program designed to meet the educational and developmental needs of this patient population. The program is enhanced by a city-wide collaborative group which consists of pediatric and adult renal care providers. This group meets annually to strategize ways to improve the transition program and transfer of care process in general. Ongoing evaluation will include seeking patients' input with regard to the effectiveness of the program from their perspectives. The goal of the transition program and collaborative effort is to achieve positive outcomes for this patient population.

INTRODUCTION

Kennedy and Sawyer (2008) define "transition" as the period of preparation prior to and after the event of transfer. Transfer is the actual shift of patients' care from pediatric to adult health care providers. This has been discussed extensively throughout the past two decades; however, best practice methods are not well defined as a part of pediatric subspecialty care, including nephrology. The research available is limited largely due to a lack of a substantial history of the long-term survival of pediatric patients with a variety of chronic diseases. As positive outcomes for pediatric patients with chronic diseases increase in frequency and duration, it is important to have care of these patients provided in the most appropriate medical facilities. This strategy is recommended by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine (2002) as well as the Society for Adolescent Medicine (2003) to address the developmental process of adolescents emerging into adulthood. The Society for Adolescent Medicine (2003) bases its definition of an appropriate medical facility on chronological age and developmental attainment.

The goal of transitional care is to maximize lifelong functioning through high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood (Chaturvedi, Jones, Walker, & Sawyer, 2009, p. 1055). The population requiring transitional services is increasing. The literature has recently indicated a significant improvement in success rates and as many as 90% of dialysis and transplant patients are living past 21 years old (La Rosa, Glah, Bluarte, & Myers, 2011). With increasing survival rates, combined with the goal of excellent care, the issue of transition is attracting attention because of the need for adolescents and young adults to develop the skills and capacities for long-term self-management of their health care.

The literature has identified lack of planning as one of the most common reasons for the failure of patients to move successfully from pediatric systems into adult-oriented systems, while maturity was identified as the key factor necessary for successful transfer (Watson, 2005). Overprotectiveness by parents and other caregivers has been identified as another barrier to transfer (La Rosa, et al., 2011). Recognizing that general education alone was not effectively preparing patients for the transition to adult care, it has been recommended that the transition process include both general education about the patients' diagnosis and treatment, and teaching skills that address the areas of independence and self-management of health care (Lugasi, Achille, & Stevenson, 2011). Education on managing simple health tasks such as calling in for prescription refills or scheduling appointments has contributed to more a successful transfer (Bell, 2007).

Another important aspect of the transition process is for the medical team to look beyond the "check list" of transition tasks for the patient and the inherent risks of non-adherence and, instead, emphasize the need for regular communication and understanding between the patient and medical team. This skill will likely serve them well in the new health care setting (Watson, 2005). Regular communication with adolescents/young adults throughout the transition process should ideally make them feel a sense of achievement in reaching such an important developmental milestone. The goal is to motivate them or gain their "buy-in" regarding the upcoming transfer of care and their important role in making it successful.

Improved communication between the pediatric and adult medical teams regarding barriers to a successful transfer of care has also improved the process (Watson, 2005). Both pediatric and adult care providers must be invested in a successful transfer process if it is to be accomplished optimally. Recent literature recommends joint visits between pediatric and adult providers, as well as pre-transfer visits of the adolescents/young adults to their potential adult provider systems (Lugasi, Achille, & Stevenson, 2011).

Research suggests that pediatric nephrologists and their medical teams have training in adolescent issues to be able to assist patients in becoming engaged in their complex medical regimens and promoting resilience in the face of chronic illness (Watson, 2005).

The literature also suggests that the pediatric providers have a vested interest in their patients. However, it is also recognized that pediatric facilities often have more supportive resources for patients and families than adult facilities (La Rosa et al., 2011). Pediatric providers are often accused of "spoiling" their patients and have difficulty with trusting a new provider with meeting the needs of their patients in an adult facility (Watson & Warady, 2011, p. 156). Adult providers have been found to be unprepared and lack knowledge about pediatric renal disorders and the developmental needs of adolescents and young adults transferring to their care (Watson & Warady, 2011). Because of their vested interest and resources available, pediatric teams must be knowledgeable about transitions and should ideally take the lead in the process. The Children's Mercy Hospital program in Kansas City, MO, follows this design.

PATIENT EDUCATION AND PREPARATION

Based upon the published information regarding the transition process and the clear need for transition preparedness for patients with chronic health care needs as well as their parents, a transition education program was developed and implemented by the dialysis and kidney transplant program at Children's Mercy Hospital. The program, entitled "Kidney Education for Your Success (K.E.Y.S.)," is designed to be initiated when the patient reaches age 12 (or at diagnosis of chronic kidney disease if it occurs later) and to continue until the patient is transferred to adult care. This generally occurs prior to the patient's 22nd birthday. The education is provided as part of standard care to all dialysis and kidney transplant patients at Children's Mercy Hospital. The curriculum is presented in four phases (see Table 1.1) to the patients during routine clinic visits in the Kidney Center and/or Dialysis Unit at Children's Mercy Hospital during time that is specifically allocated for transition education. There are currently 13 dialysis and 60 transplant patients participating in the program.

Phase One of the program focuses on "Finding Your K.E.Y.S." This phase is directed toward patients who are 12 to 14 years of age. The goal of this phase is for patients to begin learning the basics about their health and its effects on their everyday life. As they learn about these issues from the K.E.Y.S. program, they are encouraged to start thinking about ways to take a more active role in their medical care. In this phase, education is provided by a member of the medical team and patients participate by completing learning activities to reinforce the teaching. The medical team member makes sure patients accurately grasp essential concepts prior to proceeding to the next phase.

Phase Two focuses on "Sharing Your K.E.Y.S." This phase occurs when patients are between 15 and 17 years of age. In this phase, the patients have opportunities to show the medical team the skills and knowledge gained thus far in the program through the teach-back method (asking patients to explain or demonstrate what they have been told). This is a time for patients to work with the medical team to develop new skills and improve on existing ones (knowing their lab values, knowing each of their medications and why they are taking them, identifying employment/education goals for their future), all designed to help the patients become expert in their own medical care.

Phase Three focuses on "Turning Your K.E.Y.S." This phase occurs between 18 to 20 years of age and is designed to encourage patients to gain real-life experience and to build on their involvement in their medical care. This occurs by incorporating information from the classes into their everyday lives, such as ordering medication refills, scheduling medical appointments, and participating in direct communication with their medical team. The incorporation of these concepts allows patients to practice self-reflection (looking inward) and self-care techniques. This phase gives patients opportunities to identify how their disease impacts their lives and emphasizes the importance of effective coping and management skills. By this time, patients will be able to demonstrate knowledge of their kidney disease and begin taking more responsibility for their future medical care.

Phase Four of K.E.Y.S. focuses on "Unlocking the Door." This phase begins at the completion of Phase Three and should conclude by age 22. This final phase incorporates the actual transfer of care to an adult provider. The team works with patients to facilitate the completion of a transfer checklist, which includes scheduling a tour of the adult facility and meeting the adult care staff; identifying plans to get labs and medications; and addressing any insurance, pharmacy or medication issues that may arise during the transfer.

COLLABORATION

In addition to the collaborative, educational approach developed for patients through the K.E.Y.S. program, the Children's Mercy Hospital team recognized the importance of partnering with adult renal providers in the Kansas City community with the goal of identifying barriers and solutions for a successful transfer of patients. In a freestanding children's hospital such as ours, pediatric care providers frequently do not have regular interaction with adult providers who will ultimately care for the transitioned patients. To bridge this gap and provide an avenue by which this communication could occur, a city-wide dialysis and kidney transplant collaboration was developed in 2010 to improve the transition education and transfer of care processes.

Table 1.1 *The K.E.Y.S. Program*

Phase	Age of Patient	Education Goal	Education Curriculum
Phase 1	12–14	Didactic and interactive education to teach concepts and skills	Diagrams, crossword puzzles, matching exercises, hands-on demonstrations, and word-find activities that all pertain to learning the patient's diagnosis and how to be involved in medical self-care
Phase 2	15–17	Reinforcement of concepts and skills by utilizing the "teach-back" method, where the patient tells the provider what has been learned	Fill-in-the-blank and true/false worksheets designed to assess knowledge of the skills and concepts presented
Phase 3	18–20	Incorporation of concepts and skills into real-life situations. The patient is able to express how each concept and/or skill impacts his/her life.	Worksheets with open-ended questions that allow each patient to express how previously learned concepts and skills are applied/incorporated into daily living
Phase 4	21 through transfer to adult care	Successful completion of the transfer of care to an adult facility	Checklist of steps to be completed to lead up to and include the actual transfer of care between providers

The initial collaborative conference was entitled "Transition: Navigating the Journey from Pediatric to Adult Care." A multidisciplinary group of pediatric providers from Children's Mercy Hospital and adult renal providers in the Kansas City area attended the meeting. The group consisted of adult and pediatric nephrologists, an adolescent medicine physician, dialysis nurses, transplant coordinators, dietitians, social workers, financial counselors, and importantly, several patients who had transitioned to adult care themselves.

The objectives for this day were to: 1) review the stages of young adult development, including the impact of chronic illness on development; 2) describe transition strategies based on published research; 3) describe the components of a pediatric transition education program; 4) discuss needs and expectations for successful transition to adult care; and 5) identify barriers and solutions to effective transition of young adults to adult care. The day consisted of a morning education program including lectures on "Trials and Tribulations of Working with Teens with Chronic Illness" by Daryl Lynch, MD; "Empowering Young Adults with Chronic Kidney Failure and Their Renal Teams in Adult Dialysis Units" by Erica Perry, MSW; and "Barriers to Adherence" by Bradley Warady, MD. The highlight of the morning was a panel presentation by the recently transferred young adults who spoke on the challenges of transitioning from pediatric to adult renal care.

The afternoon consisted of roundtable discussions to explore the barriers and solutions to the transition and transfer of care processes. Three subcommittees with the following goals were developed from the roundtable discussions: 1) "Create Independence" subcommittee: create and nurture independence among pediatric patients; 2) "Integration of Pediatric/Adult Care" subcommittee: integrate adult care concepts into the pediatric setting; and 3) "Adult Provider Information" subcommittee: provide adult provider information to pediatric patients prior to the transfer of care. Throughout the following year, a Transition Steering Committee oversaw the progress of each subcommittee to maintain organization and consistency within the collaborative effort.

The group reconvened in October 2011 to evaluate outcomes, monitor successes, and further improve the transition process. The objectives for the day were to: 1) identify current research related to transition; 2) discuss ways to utilize social media, Skype, telemedicine, and texting to enhance the transition process; 3) describe how the enhanced transition program has impacted patients, families, and staff; 4) review accomplishments of the transition workgroups; and 5) plan for pediatric and adult dialysis/transplant professionals to develop a follow-up assessment process for transition. The day consisted of a morning educational program that included a literature review of research on transition initiatives in nephrology and other disease areas by Bradley Warady, MD, and "Technology/Social Media: Ways to Enhance Transition" by Ron Nicholis, MD, and Kim Gandy, MD. In addition, two current Children's Mercy Hospital patients talked about ways they use social media, text reminders, phone alarms, and email in their lives, and provided suggestions for using technology in the medical setting to improve adherence.

In addition to the presentations, the subcommittees formed at the 2010 collaborative meeting reported their development and progress. The "Create Independence" subcommittee reported on continued progress with implementation of the K.E.Y.S. transition program. From 2010 to 2011, multiple patients who were planned to be transferred to one local transplant program, St. Luke's Hospital, were able to attend a "meet and greet" session at Children's Mercy Hospital.

At this event, these transitioning pediatric patients had an opportunity to meet with the adult care team, prior to the transfer of care. Due to the success of the intervention, "meet and greet" sessions with other local programs that admit some of our transitioning patients are being discussed as well. There has also been an increase in the use of MedActionPlan.com text message reminders (medication schedule and discharge instructions) that have fostered independence and have resulted in improved adherence with medical care responsibilities.

The "Integration of Pediatric/Adult Care" subcommittee created four forms to utilize in the transition/transfer process. The following forms focus on the last two years of patient care in the pediatric setting: 1) Transition/Transfer Process Form: This form outlines the steps required for a successful transfer of care from pediatric to adult centers. Tasks are identified in a timeline and are clearly marked by each responsible medical team member. Tasks begin two years prior to transfer and continue for 90 days post-transfer. Each form is modality-specific. Major differences between dialysis and transplant forms are that the Children's Mercy Hospital social worker attends the 30- and 90-day care plan meetings at the transitioning dialysis patient's adult facility. Hemodialysis patients will dialyze in the adult facility for one week prior to the transfer of care and return to Children's Mercy for debriefing and discussion regarding their experiences. 2) Communication Form: This form provides an opportunity for the patients to make the adult medical care providers aware of how they prefer to communicate. It is completed with the assistance of the pediatric social worker. The form is sent to the adult program prior to the transfer of care. 3) Patient/Provider Questionnaire: This form was developed by the subcommittee with the help of a few recently transitioned patients. It provides a list of questions for patients to ask when visiting or evaluating an adult program prior to the transfer of care. 4) Transition Care Plan: This form is used to facilitate discussion between the pediatric medical team and the patient after the initial visit with the adult nephrologist or during the one week of hemodialysis during the transition period. The medical team at Children's Mercy helps the patient complete this form about his or her experience, with specific attention to questions that remain unanswered, or anything the patient may feel unprepared for prior to completing the transfer process. This completed form is subsequently sent to the adult program just prior to the transfer of care.

The "Adult Provider Information" subcommittee reported the development of a resource notebook with helpful information about area adult nephrology facilities and programs. The book currently has information about local adult dialysis and transplant programs in the Kansas City area. It contains pictures of facilities and staff, general operation guidelines, and helpful hints for each program. It provides another way for patients from Children's Mercy Hospital to become familiar with different adult programs without having to physically visit each one.

During the afternoon, round table discussions were held to explore different aspects of the transition and transfer of care processes. The goal for Roundtable One was to identify patient strengths, challenges, and level of responsibility for medical care at the time of transfer, and to identify how transition education may continue after transfer has occurred. Ideas for improvement included: instituting monthly clinic visits with the adult nephrologist for at least the initial three months following the transfer of care; attempting "buddy transfers" by transferring more than one patient at a time, with patients using each other as sounding boards and for encouragement; and developing a community-based support group as a resource for transitioned patients, functioning somewhat like an alumni group; and planning "meet and greet" sessions throughout the year and having patients start attending the sessions two years prior to transfer.

The goal for Roundtable Two was to create a post-transfer tool to collect data from patients who have transitioned to adult care. Discussion focused on what information to collect from transitioned patients, as well as how and when to collect it. Recommendations for the questionnaire/tools included: 1) The survey would be administered at intervals of one and six months, post-transfer of care. The questions would remain consistent. 2) Questions would target the specific interventions implemented in the transition program (K.E.Y.S. program, "meet and greet," tour of the adult facility, etc.). 3) Develop an independence tool that rates patients' success on various items, including adherence, goals, and quality of life.

CONCLUSION

It is evident from the research that transition education programs should begin in preadolescence, and should include involvement of both pediatric and adult-care providers. These programs are essential for a successful transfer of care process. Post-transfer, the next step in the process is to evaluate, from a patient's perspective, if the transition program is effective, and to modify it to meet the needs of patients and health care providers alike. It will be a key goal to fully implement the ideas developed by the transition collaboration group to establish consistent practices surrounding the transfer of care. A standardized and comprehensive pediatric transfer of care program is an essential component of any plan designed to provide high-quality health care to adolescents and young adults with chronic health conditions. As the quality of medical care improves and pediatric patients with chronic diseases live longer, providers will need to continue to identify best practice models for this growing population. Programs and efforts like those being conducted at Children's Mercy Hospital and similar institutions will hopefully result in positive outcomes for patients.

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Actions and Recriminations

Book Review by Wendy Funk Schrag, LMSW, ACSWB

No Good Deed: A Story of Medicine, Murder Accusations, and the Debate Over How We Die
by Lewis M. Cohen, MD, ISBN-13: 9780061721779; HarperCollins; 272 pages; $14.99

Lewis Cohen, MD, has written an accessible book containing comprehensive interviews and information about a variety of legal and ethical issues surrounding end-of-life medical care and decision making. Cohen takes the title from a well-known quote by Clare Boothe Luce that foreshadows the content: “No good deed goes unpunished.” Cohen, a psychiatrist and palliative care specialist, begins by discussing what his book is not. It is not about medical professionals who practice physician-assisted suicide or about catastrophic situations involving medical ethics, such as Hurricane Katrina. Rather, Cohen’s book describes accusations over clinical procedures and decisions considered to be both legal and ethical. Cohen examines specific medical cases where well-meaning medical professionals, offering what they perceived to be reasonable end-of-life care, are later accused by others (professionals, family members, etc.) of murdering or euthanizing patients.

The main case study described throughout the book involves two renal nurses caring for a woman in an intensive care unit at Baystate Medical Center in Massachusetts. The patient was near the end of her life, and her family had already made the decision to discontinue dialysis. The two nurses, Amy Gleason and Kim Hoy, were accused by a nurse’s aide of murdering the patient. It was some time after the patient died that detectives came knocking on Gleason and Hoy’s doors. What followed were several years of investigation, a trial for murder, and an ongoing struggle for resolution by both medical professionals and the patient’s family.

Among the many issues Cohen discusses in the book, these specific ones stood out for me:

- Cohen states that there is no “clean, impersonal, and easy way” to shift from providing curative care to palliative care. “There is no computer that a doctor simply turns off, no magic switch that gets thrown, no timer that runs out. It usually falls upon a nurse to go to the bedside and carry out a series of actions, and complicated communications that allow the patient to die in as comfortable a manner as possible.” Emphasizing that often physicians are not even present for deaths, much responsibility falls upon nurses (and perhaps other medical professionals as well) to follow policies and procedures, document closely, make decisions, and interact with others in a manner that is medically and ethically defensible.
- Cohen interviews other medical professionals who have been accused of murder or unethical actions that led to premature deaths. The loss of confidence and the self-doubt that follow many medical professionals for years can become disabling. Some leave the medical field, even if they are found to be innocent. Some suffer from stress-induced illnesses and depression. As Cohen states, “…these conflicts can tragically mangle the lives of some of our finest caregivers.”
- Cohen interviews accusers and helps bring their perspectives to light. Without professional medical knowledge, family members or other professionals can misunderstand ethical actions by medical professionals.
- Resolution, whether focused on ourselves or healing relationships with others, is important for all to be able to move on with their lives following these very difficult situations.

As nephrology social workers who relate professionally to patients, families, and other nephrology professionals, we have an obligation to others as well as ourselves, to evaluate our interventions in end-of-life care through ongoing education and self-reflection. Someone once said to me that nephrology social workers are the conscience of the dialysis unit. If this is true, much responsibility lies with us to not only ensure that we are acting ethically, but that we are also influencing and supporting others to act ethically as well.

Improving communication between staff and patients is one of our vital functions as well. We have an opportunity to be a key part of the treatment process by clarifying for patients and families the rationale behind certain decisions. Further, we can convey to the treatment staff dissatisfaction or urgent concerns before they reach a potential flash point. Though we may not always have perfect results, our continuing efforts to de-escalate could stop situations like the above before they happen.

NATIONAL KIDNEY FOUNDATION
2013 SPRING CLINICAL MEETINGS
APRIL 2–6, 2013

CKD-ESRD: Vascular Access

3 **Motivational Interviewing to Overcome Barriers to Placement or Cannulation of Permanent Access**
Sharon Essick, Shaun Boyd, Alison Dunklee, Scott Franklin, Dawn Burton, Carolina Gilbert, Jamece Mckinley, Stephanie Best. DaVita, Inc., Denver, CO, USA

CKD-ESRD: Other

2 **Incidence of Missed and Shortened Hemodialysis Treatments in a Large Urban Hemodialysis Unit. Effect on Mortality. Impact of QUAPI Derived Multidisciplinary Protocol on Outcomes**
John D'Avella, Stephanie Antonelli, Mary Jane Porado, Donna Kelly. Hartford Hospital Dialysis, Hartford, CT, USA

4 **Quality of Life Issues for Children with Kidney Disease: Lessons Learned and Recommendations for Professionals**
Keenan Fisher. University of South Carolina, Columbia, SC, USA

7 **Increasing Patient Awareness of an Advance Care Planning Guide Using a Multimedia Approach**
Kelly Rivers, Anita Vidic, Donna Belmore. York Region Chronic Kidney Disease Program, Mackenzie Health, Richmond Hill, Ontario, Canada

8 **Impact of In-Home Education Programs on the Graduation Rate of Young Adults with Kidney Disease**
Lori Sanderson[1], Lee Anne Gridley[1], Peter Yorgin[2]. [1]Loma Linda University Children's Hospital, San Bernardino, CA, USA; [2]Rady Children's Hospital, San Diego, CA, USA

Home Dialysis: Home Hemodialysis Peritoneal Dialysis

10 **Characteristics of Selected KDQOL Survey Results with Home Dialysis Patients**
Dodie M. Stein[1], Janet L. Welch[2], Michael A. Kraus[1]. [1]Indiana University Health, Indianapolis, IN, USA; [2]Indiana University School of Nursing, Indianapolis, IN, USA

Transplantation

1 **Patient Navigation: A Promising Intervention to Promote Kidney Transplant Parity**
Teri Browne[1], Avrum Gillespie[2], Tamara Savage[1], Alison Brown[1], L. Ebony Boulware[3]. [1]University of South Carolina, Columbia, SC, USA; [2]Temple University, Philadelphia, PA, USA; [3]Johns Hopkins University, Baltimore, MD, USA

5 **"*We're Not Going to Say it's Suffering, We're Going to Say it's an Experience.*" The Lived Experience of Mothers of Children Who Have Undergone Kidney Transplantation**
Andrew Mantulak. King's University College at Western University, London, Ontario, Canada

Other

6 **Phosphate Binder Self-Management in Dialysis Patients: A Qualitative Study**
Joseph Merighi[1], Teri Browne[2], Tamara Savage[2], Karen Ryals[3], Kerri Cavanaugh[4]. [1]Boston University School of Social Work, Boston, MA, USA; [2]University of South Carolina College of Social Work, Columbia, SC, USA; [3]American Association of Kidney Patients, Tampa, FL, USA; [4]Vanderbilt University Medical Center, Nashville, TN, USA

9 **ESRD: Medication Self-Management and Parity**
Tamara Savage. University of South Carolina, Columbia, SC, USA

11 **Relationship Between MSW Time Spent in Clinical Tasks and Facility Quality Scores and Patient Satisfaction Ratings**
Leslie Wilfong. Fresenius Medical Care, Franklin, IN, USA

1. PATIENT NAVIGATION: A PROMISING INTERVENTION TO PROMOTE KIDNEY TRANSPLANT PARITY

Teri Browne,[1] Avrum Gillespie,[2] Tamara Savage,[1] Alison Brown,[1] & L. Ebony Boulware[3]
[1]University of South Carolina, Columbia, SC, USA; [2]Temple University, Philadelphia, PA, USA; [3]Johns Hopkins University, Baltimore, MD, USA

Patient navigation is an intervention that has shown significant promise in improving cancer and other chronic illness outcomes. Patient navigation was created to help ameliorate health disparities and uses a professional or lay "patient navigator" to help patients navigate through different barriers to treatment. Despite frequent use of patient navigation in other chronic illnesses, the kidney disease community has not widely embraced this intervention as of 2012. As a first step in exploring the use of patient navigation by social workers with kidney disease patients, particularly as a possible way to promote kidney transplant parity, a literature review was conducted to examine the use of patient navigation in kidney disease and other chronic illnesses. An online search was conducted from January 2012 to October 2012 using MEDLINE, PubMed, Ovid, CINAHL, and PsychLIT databases to identify research and summarize findings from meta-analyses, systematic reviews, clinical reviews, and clinical trials published in English between January 1985 and October 2012, as they relate to patient navigation in kidney disease and other chronically ill populations. The results of this literature search suggest that patient navigation is a promising intervention that may help improve kidney disease outcomes, including kidney transplant parity. This poster will also discuss recommendations for the use of patient navigation to promote kidney disease and kidney transplant.

2. INCIDENCE OF MISSED AND SHORTENED HEMODIALYSIS TREATMENTS IN A LARGE URBAN HEMODIALYSIS UNIT. EFFECT ON MORTALITY. IMPACT OF QUAPI DERIVED MULTIDISCIPLINARY PROTOCOL ON OUTCOMES

John D'Avella, Stephanie Antonelli, Mary Jane Porado, Donna Kelly, Hartford Hospital Dialysis, Hartford, CT, United States.

There is no recent data on the incidence of missed or shortened hemodialysis treatments in a large urban setting. We tracked missed and shortened treatments as a quality indicator. When the incidence of missed and shortened treatments was noted, a QUAPI project was undertaken to study why and to design a protocol to correct it. Patients were interviewed and a root cause analysis was done. A protocol was developed involving a multidisciplinary approach to address missed and shortened treatments. Barriers to treatments were addressed and patients were educated about the risks. If patients missed more than 3 treatments per quarter, a multidisciplinary meeting with the patient and family was facilitated. The unit delivers approximately 26,208 treatments per year. In 2010, 640 treatments were missed (2.4%). Patients who missed 4 or more treatments had a mortality risk of 31% vs unit mortality of 19.6%. With the protocol in 2011, missed treatments fell to 516 (decreased 19%) and in 2012 1st quarter data annualized to 392(decrease 39%). This will result in added revenue of $55,056. Shortened treatments did not initially change 198/199 2010/2011 (they were included in the protocol). Since inclusion, the annualized rate for 2012 is 172 (decrease of 14%). The most common reason for missed/shortened treatments was not feeling well and cramping. Missed treatments have a negative impact on patient mortality and unit revenue. Through a protocol which discovers reasons for missed/shortened treatments; relies on patient and family education and involves all members of the health care team; it is possible to reverse this trend.

3. MOTIVATIONAL INTERVIEWING TO OVERCOME BARRIERS TO PLACEMENT OR CANNULATION OF PERMANENT ACCESS

Sharon Essick, Shaun Boyd, Alison Dunklee, Scott Franklin, Dawn Burton, Carolina Gilbert, Jamece Mckinley; Stephanie Best
DaVita Inc., Denver, CO, USA

Introduction: Despite the risks associated with Central Venous Catheters (CVC), some patients refuse permanent access for non-medical reasons. We engaged patients who were refusing permanent access, or cannulation of permanent access, for non medical reasons in Motivational Interviewing (MI) to see if these patients would obtain permanent access, or cannulation of permanent access, by the end of the study period.

There were four patients in the study from three dialysis centers in a large dialysis organization. The project team consisted of five social workers, one RN, and one Patient Care Technician. The project team participated in weekly calls for two months to become familiar with MI techniques. MI interventions began the first week of January 2012 and ended the last week of March 2012. Weekly calls continued throughout the study period to review patients' status, and to offer suggestions on how to help the patients move through the stages of change. Project team members met with patients an average of three times a month.

Results: By the end of the study period three out of the four (75%) patients either obtained permanent access or allowed cannulation of permanent access. The fourth patient dropped out of the project when he traveled to another country for two months during the study period.

Conclusion: The project results lend themselves to a broader study.

4. QUALITY OF LIFE ISSUES FOR CHILDREN WITH KIDNEY DISEASE: LESSONS LEARNED AND RECOMMENDATIONS FOR PROFESSIONALS

Keenan Fisher, University of South Carolina, Columbia, SC, USA

Kidney disease and its treatments result in unique quality of life stressors for children under the age of 18. Dialysis and transplant social workers and interdisciplinary professionals need distinct interventions to help minimize the burden of kidney disease on pediatric patients and their family members. Before testing different interventions which could potentially maximize pediatric quality of life (QOL), a literature review was completed to research the particular facilitators and barriers to QOL for this specific population. Also, a search on the current interventions which relate to pediatric kidney disease patient QOL was conducted. The literature search was conducted October 2012 to November 2012 and included findings from different databases including, PubMed, Academic Search Complete, AltHealthWatch, Applied Social Sciences Index and Abstracts, Social Work Abstracts, and Social Service Abstracts. The databases were used to help identify and summarize the findings from clinical trials, articles and journals, and reviews specifically related to QOL of pediatric patients with kidney disease. These were all published in English from January 1990 to November 2012. The results provide evidence that the pediatric kidney disease community needs particular interventions to improve QOL for not only the patient, but their families as well. The literature suggests that a variety of social determinants of health strongly contribute to patient QOL. An overview of measurements for pediatric QOL will be provided, including recommendations for professionals which can help this specific population's outcomes.

5. *"WE'RE NOT GOING TO SAY IT'S SUFFERING, WE'RE GOING TO SAY IT'S AN EXPERIENCE."* THE LIVED EXPERIENCE OF MOTHERS OF CHILDREN WHO HAVE UNDERGONE KIDNEY TRANSPLANTATION

Andrew Mantulak King's University College at Western University, London, Ontario, Canada

Advances in the surgical and immunological aspects of organ transplantation have resulted in significant improvements in the long term outcome and survival rates, making kidney transplantation the optimal therapy for children with end stage kidney disease. The goal of transplantation is no longer just graft survival and getting children to an acceptable level of physical health, but to improve their overall quality of life. In the limited literature available, however, there continues to be a negative impact reported on overall family functioning despite the reported good health and quality of life for the transplanted child. Specifically, the stressors of the burden of care experienced by mothers (who are socially ascribed the caregiving role for chronically ill children) is notable. This research utilizes a hermeneutic phenomenological approach to examine the lived experience of mothers of children who had undergone kidney transplantation. A sample of 7 mothers from southwestern Ontario (Canada) volunteered to participate in a process of in depth interviewing. Findings of the study illuminate that the experience of mothering in the context of pediatric kidney transplantation are reflected in (1) the significance of relationships to the experience of self , (2) the lived experience of time (3) the lived experience of space, and (4) opportunity for the growth and personal development. This research identifies that while mothering a child with a kidney transplant is fraught with physical, social and emotional challenges, there are opportunities for the development of skills and personal growth within the experience.

7. INCREASING PATIENT AWARENESS OF AN ADVANCE CARE PLANNING GUIDE USING A MULTIMEDIA APPROACH

Kelly Rivers, Anita Vidic, Donna Belmore, York Region Chronic Kidney Disease Program, Mackenzie Health, Richmond Hill, Ontario, Canada.

A common challenge experienced within dialysis programs is how to disseminate advance care planning (ACP) information to patients, while respecting the sensitive nature of this topic and being mindful of the amount of time already devoted to hemodialysis (HD) treatments. Various formats to determine the best approach of addressing the ACP needs of the patients were explored.

A focus group was held with both HD staff and patients requiring HD to determine essential information to include in an ACP guide and how to effectively disseminate this information. The ACP guide, in the form of a booklet, titled "It's My Decision" was created to help patients facilitate discussions with their family members and trusted friends about their wishes for future health and personal care decisions. The ACP guide includes a section on frequently asked questions, definitions, and a detachable portion that patients can complete to document their wishes and Powers of Attorney (POA).

During initial Social Work assessments and on a case-by-case basis, patients requiring HD were made aware of ACP and the availability of "It's My Decision". In addition, various formats, including: education sessions, handouts, and bulletin board postings were used. To further increase patient awareness of the ACP guide, a DVD presentation was created. The DVD was available to view on the patient televisions, on designated channels, in all four HD units while they were receiving treatments. Following the implementation of the DVD, a patient survey was distributed to obtain their feedback.

With the addition of the DVD, this multimedia approach has resulted in over 4.5 times (from 12 to 67) more patients requesting "It's My Decision". In addition, 87% of patient survey responses indicated that the information in the DVD was useful to them. This multimedia approach has helped to increase patient awareness about the importance of discussing ACP and completing POA for Personal Care and Property.

6. PHOSPHATE BINDER SELF-MANAGEMENT IN DIALYSIS PATIENTS: A QUALITATIVE STUDY

Joseph Merighi[1], Teri Browne[2], Tamara Savage[2], Karen Ryals[3], Kerri Cavanaugh[4]
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Phosphate binder medication use reduces serum phosphorus and is associated with improved bone and mineral disorders and cardiovascular mortality in dialysis patients. The main study aim is to understand factors that facilitate and prevent phosphate binder self-management, so that innovative and culturally relevant interventions can be developed to promote long-term medication use.

Primary data were gathered from five, 90-minute, small-group interviews with hemodialysis patients ($N = 17$) in Atlanta, GA. The sample profile is: 12 women, 13 African American, mean age = 53 (SD=10.9), dialysis vintage = 87 months (SD=59), and total pills consumed per day = 16 (SD=13). A constant comparative method was used to identify themes that emerged from a line-by-line review of the interview transcripts.

Participants described three key factors that facilitated phosphate binder use: family, peer, and provider support; placing binders in multiple locations; and seeing images that depict health consequences associated with high serum phosphorus. Further, they identified several salient barriers to using binders as prescribed: cost, preserving privacy by not taking pills in public, and regimen complexity.

The study findings provide the basis for the development of targeted interventions that can reduce health disparities by bolstering patient self-management, improving health outcomes, and reducing costs associated with medication non-adherence in the end-stage renal disease population, as well as in other chronically ill populations.

8. IMPACT OF IN-HOME EDUCATION PROGRAMS ON THE GRADUATION RATE OF YOUNG ADULTS WITH KIDNEY DISEASE

Lori Sanderson, Lee Anne Gridley, Peter Yorgin

Kidney transplant recipients (KTXP) and young adults with chronic kidney disease (CKD) have many academic and physical challenges as a result of their illness. Most school systems can provide home schooling with self-paced learning material and in some cases a tutor or credentialed teacher for children with chronic disease.

A retrospective analysis of high school graduation rates (before their 19th birthday) for KTXP and CKD patients was performed. There were 54 participants in the study sample. High school graduation positively correlated with traditional school (OR: 3.778, $p < 0.001$), parents who attended college and no state or federal aid. Participation in home education programs was positively correlated with working parents, kidney transplantation, Hispanic ethnicity, English language spoken at home, and parents who were not college educated.

Limitations of the study included the retrospective design of the study, and lack of information detailing educational and motivational support at home. The ability to generalize study findings to the general population may be hampered by the unique patient population, which consisted of those who were predominately low-income and Hispanic.

In-home education programs for patients with kidney transplants and chronic kidney disease were associated with lower graduation rates. Close monitoring of patients who are enrolled in home education programs by multidisciplinary medical teams may be warranted.

9. ESRD: MEDICATION SELF-MANAGEMENT AND PARITY

Tamara Savage
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Poor medication self-management leads to increased risk for morbidity and mortality in ESRD patients. Much research also has shown that there are poor rates of medication self-management in the ESRD population. In addition, there is research that race/ethnicity is associated with unsuccessful medication self-management. Specifically African Americans have poorer rates of medication self-management when compared to Whites. As a first step in exploring poor medication self-management as it relates to parity, a literature review was conducted to examine the factors that contribute to this lack of parity in in the ESRD population. An online search was conducted from August 2013 to December 2013 using MEDLINE, PubMed, Ovid, CINAHL, and PsychLIT databases to identify research and summarize findings from meta-analyses, systematic reviews, clinical reviews, and clinical trials published in English between January 1985 and December 2013, as they relate to factors associated with patient medication self-management and parity. The results of this literature search suggest that there is indeed a problem of parity as it is related to medication self-management in the ESRD population. Many barriers are explicated in the extant literature; however, little pertain to the unique circumstances of minority group living in a society where racism is prevalent. Therefore, further research needs to be conducted to ascertain the unique factors related to unsuccessful medication self-management in minority ESRD patients.

10. CHARACTERISTICS OF SELECTED KDQOL SURVEY RESULTS WITH HOME DIALYSIS PATIENTS

Dodie M. Stein[1], Janet L. Welch[2], Michael A. Kraus[1]
Indiana University Health, Indianapolis, IN[1], Indiana University School of Nursing, Indianapolis, IN[2]

The *Kidney Disease Quality of Life* (KDQOL) survey is mandated by the Centers for Medicare & Medicaid Services as part of the social worker's comprehensive assessment of dialysis patients. Current normative data overwhelmingly represent in-center patients. There has been no large study reported to date of health-related quality of life for home dialysis patients. A better understanding of the health-related quality of life of home dialysis patients would assist social workers and other staff in helping patients improve their quality of life.

The purpose of the current study was to describe health-related quality of life for both daily home hemodialysis and peritoneal dialysis patients from a single, large unit and explore differences between the home dialysis modalities. Specifically, the Physical Component Summary (PCS) score and the Mental Component Summary (MCS) score of the KDQOL, thought to be significant predictors of hospitalization and/or death, were used for primary comparisons. Descriptive data will be reported from the most recent administration of the KDQOL-Complete survey for the calendar year 2012. Data will be compared for demographic (age, gender, race, home dialysis modality) and illness (diabetic status, length of time on home dialysis, type of access, dialysis adequacy, albumin, incidence of hospitalization) characteristics. Preliminary analyses suggests substantial differences for both demographic and illness characteristics.

Implications for social worker and staff follow-up with patients will be presented.

11. RELATIONSHIP BETWEEN MSW TIME SPENT IN CLINICAL TASKS AND FACILITY QUALITY SCORES AND PATIENT SATISFACTION RATINGS.

Leslie Wilfong, Fresenius Medical Care, Franklin, Indiana, USA

. Purpose: The researcher intended to discover if the percent of work time the Renal MSW spends providing clinical services has an impact on the facility's quality scores (Ultrascore) or if it has an impact on patients' satisfaction with the MSW's social work services provided in the facility. . . . . .

. Methods: The NKF-CNSW Time Study tool was completed by 26 MSW's employed with Fresenius Medical Care in the Indiana Region for one month between September 2011 and December 2011. The results were summarized on a spreadsheet, specifying percent of time spent in Clinical tasks (Assessments, Care plans, Quality of Life Surveys, Counseling, Patient Education), Administrative/Clerical Tasks, Insurance tasks and 'Other' (time off, breaks, travel). These results were correlated with the quality scores of the social worker's facilities. (The quality score, or Ultrascore, is derived from facility performance on key indicators such as adequacy, albumin, and hospitalization.). Additionally patients' ratings of satisfaction with Social Work services was compared with the percent of clinical time, the amount of time spent driving during work hours and amount of time spent making arrangements for traveling patients. No statistical analysis was applied, only straightforward observation of trends.

. Results: The facilities of the five MSWs with the greatest percent of clinical time had higher quality scores, as a group, than the facilities of the MSWs with the lowest amount. The patients in facilities with a higher percent of MSW clinical time rated their satisfaction with the MSW higher. Facilities which had less clinical time or more driving and patient travel related tasks had lower satisfaction ratings.

. Conclusion: MSW time spent with clinical tasks has a positive impact with both quality and satisfaction in the sample studied.