The Journal of Nephrology Social Work

Council of Nephrology Social Workers

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- One Social Work Group's Process of Conducting an Outcomes-Driven Project
- Emotional Exhaustion and Workload Demands in Renal Social Work Practice

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CONTENTS

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One Social Work Group's Process of Conducting an Outcomes-Driven Project

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Renal social workers across the country are being encouraged by the Council of Nephrology Social Workers to incorporate the outcomes-driven model of nephrology social work into their social work practice with dialysis patients. Initially this model of practice may seem overwhelming, not very useful, or too complicated to some renal social workers who are not used to quantifying their interventions. In spite of initial suspicion and cautious hopes, a small group of social workers at Saint Alphonsus Nephrology Center in Idaho decided to catch the outcomes-driven practice wave. This paper describes the process this group went through in their experience with an outcomes-driven practice model project.

Key Words: *outcome-driven model; nephrology social work; fluid education; kidney disease*

Thank you to Janine Neiwurth, RD, LD at Saint Alphonsus Nephrology Center, Twin Falls facility, for sharing information and handouts that were used during the interventions.

The Outcomes-Driven practice model of nephrology social work is being written about and discussed increasingly in nephrology social work circles. There have been several training programs that tout the efficacy of this model of nephrology social work. According to the Nephrology Social Work: An Outcomes-Driven Practice Model training manual (Johnstone et al, 2003) "an outcomes-driven practice model for nephrology social work will change the practice of nephrology social workers, expand the role of the nephrology social worker, and is necessary due to the changing health care delivery system and the changing CKD population." With regard to nephrology social work projects and interventions, the method "launch it, measure it, report it" (Johnstone, 2003) will put one on the right path to outcomes-driven nephrology social work.

A small group of five social workers at Saint Alphonsus Nephrology Center in Idaho decided to accept the challenge of conducting a project implementing the outcomes-driven practice model of social work. This report will discuss our efforts and our challenges in conducting such a project as well as what we learned from the experience. Because fluid management has been one of the most difficult challenges for our patients with end stage renal disease, we decided to focus our project on that subject. Specifically, we wanted to carry out an experiment to see if our psychosocial interventions would impact the interdialytic weight gain (IDWG) of a group of our patients who struggled with managing their IDWG. We knew starting out that many patients find fluid restriction to be the hardest part of living with hemodialysis (Christenson, 1995). The experiment was the first time this particular group of social workers worked together on a project of this nature and the idea initially seemed overwhelming to some. While some were enthusiastic about trying out the new model of nephrology social work, others were skeptical. After several meetings, however, the group was able to come to a consensus on what exactly the project would entail. Because the thought of doing a "research project" seemed like more than we had the time or resources to tackle, we decided to simply do an evaluation of our social work intervention. Our goal was to compare a group of patients who received social work intervention with a group of patients who did not receive it. We agreed that, at the very least, an evaluation of our interventions would provide useful information for our practice.

METHODS

Participants

The participants were all hemodialysis patients with diagnoses of end stage renal disease from a variety of causes. They were recruited from four of the six Saint Alphonsus

Nephrology Center facilities in southwest Idaho and eastern Oregon. In order to ensure the project would be manageable we used a small sample of 50 subjects.

We utilized a purposive sampling method of obtaining subjects. The RNs in the four facilities identified 50 patients who had difficulty with their IDWG. Patients eligible for the study were those who met the following criteria: 1) each had been on dialysis for at least six months, 2) each had not been hospitalized for more than three consecutive days in the past six months, 3) each had a cognitive status allowing them to give informed consent, and 4) each had a history of consistently coming to dialysis fluid-overloaded (four or more kilos over their estimated dry weight). The cognitive status of the patients was evaluated by the social worker who had the most familiarity with the patient through various interviews and their overall assessment of the particular patient. The total number of participants was divided in half. Half of the participants received the social work intervention, comprising the intervention group, and half did not, comprising the control group. The intervention group received weekly psychoeducational interventions by the social worker in addition to the standard education provided by the renal team. The control group received only the standard education provided by the renal team. Patients were assigned to either the intervention group or control group based on their verbal consent to receive the social work intervention that was obtained by the social workers after the RNs identified them as possible subjects. Confidentiality was maintained by assigning coded letters to each subject that were used when compiling data.

Measure

We designed a simple pre-test/post-test study design to evaluate our intervention. Fluid levels served as the dependent variable and the social work intervention as the independent variable. We obtained an average IDWG for each patient for the three months (12 weeks) prior to the intervention. The average was obtained by adding up the IDWG between treatments for each patient and dividing that number by the number of dialysis treatments they had. At the end of the eight-week intervention we again measured the average IDWG for each patient using the same formula, enabling us to compare their average IDWG before intervention to their average IDWG during the eight-week intervention. We measured again two months later, to give us an idea of whether or not patients were able to maintain any improvement made.

Table 1. Fluid Management Project

Participant Demographics *(n=40)*

		Intervention Group	Control Group
Gender	M	55%	60%
	F	45%	40%
Age	19-40 yrs	20%	10%
	41-64 yrs	60%	60%
	65+ yrs	20%	30%
Race Ethnicity			
	White	75%	75%
	Black	5%	0%
	Hispanic	20%	20%
	Native American	0%	5%
	Other	0%	0%
Marital Status			
	Married or cohabitating	50%	45%
	Single, divorced widowed, or separated	50%	55%
Diabetic Status			
	Diabetic	70%	70%
	Nondiabetic	30%	30%

Procedure and Intervention

Each social worker met individually once per week (for the eight weeks of the intervention phase) with each of the five patients in the intervention group assigned to them. The meetings took place chairside during the patients' dialysis treatments and lasted approximately 20 minutes each.

The interventions used were psychoeducational and behavioral in nature and had two components. The first was to provide education around the idea that a high level of fluid intake is a modifiable cardiovascular disease risk factor. The second component of the intervention focused on addressing psychosocial factors that contribute to nonadherence to prescribed fluid intake levels (such as stress or control issues) and on providing behavioral training to individually shape lifestyle and fluid-adherence behaviors. In order to establish some degree of uniformity in the intervention, each social worker followed a predetermined schedule of handouts and topics of discussion to start out the visits. These included focus areas such as the role of sodium in fluid control, tips for dry mouth relief, risks of high fluid gains, and a discussion of various psychosocial factors that could influence fluid weight gain (stress, lack of social support, anger, control, boredom, etc). Of course, each social worker and each patient have unique personalities and therefore the visits were quite varied in their content after the first several minutes.

At the end of the eight weeks, patients were given the opportunity to complete a questionnaire related to their experience of participating in the project.

RESULTS

In terms of the evaluation of the social work intervention provided, we found the identified patient demographics of both the intervention group and the control group to be nearly identical. This is helpful when comparing the two groups. At the end of eight weeks of intervention, 80 percent of the patients in the intervention group showed a positive change compared to 60 percent of the patients in the control group. Eight weeks later, measurements taken again showed that in both groups, 58 percent of the patients had improvement in their IDWG compared to before the intervention (Table 1). These results echo information available in the literature, which documents that though this type of intervention yields initial success, maintenance interventions may be required to continue to secure positive outcomes (Lenart, 1998).

Positive Change in Intervention Group V Control Group

	Intervention Group		Control Group	
	8 wks	16 wks	8 wks	16 wks
Percent of patients who made positive change	80%	58%	60%	58%

Additionally, we determined that meeting eight consecutive weeks with the patients to address this issue might be excessive. During the last few weeks of the intervention, the patients seemed to engage less in the process. We thought perhaps meeting for four consecutive weeks and then every other week might prove more effective and help patients maintain an interest in the subject matter. We would recommend fewer, less frequent visits with the patients, a sentiment reflected in the patients' comments on the questionnaire they completed at the end of the study.

Description of Change in Intervention Group

Intervention Group (n=20)

	8 weeks	16 weeks
Range of changes made	1%-37% less IDWG	1%-54% less IDWG
Average change made	11% less IDWG or .52 kilos	12% less IDWG or .60 kilos

In regard to our utilization of the outcomes-driven practice model, as opposed to other types of practice models, we support the claims made by its proponents. We feel it is important and valuable for social workers to be able to quantify our work and this model gives us the framework to do so. In a fast-paced medical environment physicians and directors want numbers. Nephrology social workers, and professional social workers in general, typically do not measure the impact of our practice. Therefore, we often times do not have an effective and simple way to communicate the impact of our practice to our administrators and other health care professionals with whom we work. This puts us at somewhat of a disadvantage as we try to advocate for our patients and for ourselves as professionals. It also hinders us in our efforts to expand the role of nephrology social worker to include more clinical activities that impact our patients and facilities in areas such as adherence, fluid control, depression, quality of life, number of hospitalizations, etc. In other words, we feel that if social workers engaged more often in measuring our outcomes, we would be able to more easily and clearly demonstrate the impact of our practice that would enable us to expand our role into the areas in which we feel we can make positive impacts on patient outcomes.

Furthermore, the outcomes-driven practice model more visibly demonstrates the value of social work in a nephrology setting. With our fluid project, one can easily see the difference between the control group and the intervention group at the end of the first eight weeks of intervention. There was initial success, but when the social work intervention ended, the patients in the intervention group returned to their normal patterns of fluid intake. Thus we may be able to conclude that periodic, focused social work contact and intervention may have been beneficial to the patients as they attempted to make healthy changes and that without it, they struggled to maintain their initial achievements.

In addition, our group learned several important things while engaging in this project. First, we learned a lot about outcomes-driven practice. As social workers we don't typically engage in this type of practice model. In fact, prior to this project, we collectively had minimal experience with outcomes-driven practice. We now have more skills and knowledge related to this practice model, giving us a wider range of tools to use in our practice. Also, we found that our interventions were more focused than they might otherwise have been. During the fluid project, we had a specific, identified issue and we knew the data would be measured. Therefore, we were less likely to have conversations with patients that skimmed the surface of a variety of issues, but rather, we tended to stay on a topic and go in depth with it as much as a patient would allow. Our willingness to try a new-to-us practice model demonstrated our sense of innovation, creativity, and desire to improve our practice. We showed ourselves and our administrators that we are ready and eager to look at new ways to expand and develop our practice to meet patient and facility needs.

As noted, the patients in the intervention group completed questionnaires related to their experience as participants of this project. For the most part, the patients responded that the interventions were helpful to them in their efforts to control their fluid intake.

DISCUSSION

As social workers new to the outcomes-driven concept, we found working on such a project both rewarding and challenging. Of the three phases of the outcomes-driven model, we found the first phase, "launch it," to be, perhaps, the smoothest. Our physicians and executive director were supportive of our idea and desire to initiate the project. It was by no means without its setbacks and struggles, however, as the five of us tried to get a collective vision of what it was we wanted to do and how we wanted to do it. We met several times to smooth out the details so that each social worker could feel comfortable with the project and also to gain as much uniformity in the interventions as possible. Though precautions were taken, at the end of the study period we noted that five of the patients in the intervention group received intervention different from the rest of the patients in the intervention group. Specifically, those five patients did not receive the same educational materials and frequency of social work intervention the other participants received. Because the differences were quite significant, we decided not to use the data from those patients.

The next phase of the outcomes-driven model, "measure it," proved to be the most frustrating of the three. The actual procedure for measuring the data was fairly easy to do and not too time-consuming. Social workers who love crunching numbers and don't get enough of it during a typical day of providing social work will really enjoy this part. Our biggest limitation with regard to measuring the outcomes is that we are not sure to what extent the data obtained correctly represented what we wanted to measure. We used our facility's computer data system to generate the desired data (IDWG). In more than one instance we found numbers that simply did not make sense. For example, we occasionally found numbers such as "87" where the IDWG would go. The problem there, of course, was data entry. And since we had no control over that aspect of the project, we found it somewhat frustrating.

Another technical limitation to the validity of our design was the assignment of subjects into either the control or intervention group. As this was not a random assignment, it is difficult to truly compare the two groups. Though the demographics of the two groups were nearly identical, we felt that the criteria "willingness to participate," which was used in creating the intervention group, is a big distinction and could account for some of the difference in results.

The third phase of the outcomes-driven practice model, "report it," is still under way. Basic math skills were used to obtain the results. We have compiled the data and will present it both in writing and verbally to the physicians and administrators at the next quarterly meeting.

One important lesson learned from this project is that applying the outcomes-driven practice model is achievable. Our project was small, but even small projects can yield valuable results. Another lesson learned from using the outcomes-driven practice model is that it is important to have a high level of social worker buy-in in order to carry out a project of this type. In our enthusiasm to initiate this fluid project, certain group members may have felt pressured to participate. Any type of group project requires organization and commitment on the part of each social worker involved. Without this, the interventions are at risk of being nonuniform, weakening the overall design of the study. In our case, we ended up not being able to use a significant portion of the results due to lack of uniformity of the interventions. Therefore, we recommend making sure each social worker involved truly does want to participate and is willing to do the necessary work involved in an outcomes-driven project.

It is more time consuming to use this practice model and is therefore important to be realistic in planning this type of project. We recommend starting with a small project. We also recommend there is at least one social worker involved who enjoys numbers and managing data. This is not an area of interest for many social workers but is extremely important with outcomes-driven projects. In our experiment, we were fortunate to have one social worker who wanted to take on the task of collecting all the data and compiling it into charts.

Finally, we suggest having patience with regard to the notion that the outcomes-driven practice model will change the practice of nephrology social work. While we do believe this to be a possibility, we also believe that it won't happen overnight or even after implementing one outcomes-driven project. The benefits are evident, however, and we concur with other practitioners of outcomes-driven social work, that it is worth the time and effort necessary for its implementation.

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Emotional Exhaustion and Workload Demands In Renal Social Work Practice

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This study examines the degree to which renal social workers experience emotional exhaustion and workload demands as a result of their professional practice in dialysis units. Mail survey data from a national sample of 809 respondents were used to make comparisons based on private versus public facility classification and level of involvement in specific job activities. Findings indicated that the respondents' level of involvement in counseling, clerical and insurance activities was significantly related to their self-reported levels of emotional exhaustion and workload. Implications for social work practice and research are discussed.

Key words: *emotional exhaustion; workload; dialysis; social work practice*

Acknowledgment: *The authors wish to thank members of the Northern California Council of Nephrology Social Workers for their invaluable work on the initial draft of the survey. This research was funded by a grant from the National Kidney Foundation.*

People with chronic kidney disease (CKD) require a range of psychosocial services and interventions from renal social workers. These services and interventions help patients to manage the physiological and psychological sequelae associated with the disease process. Renal social workers are central to the provision and management of psychosocial services for patients undergoing renal replacement therapy (Beder, 1999; Dobrof, Dolinko, Lichtiger, Uribarri, & Epstein, 2001; McKinley & Callahan, 1998; McKinley, Schrag, & Dobrof, 2000). 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 (Dobrof et al., 2001; McKinley & Callahan, 1998; MccKinley et al., 2000; Russo, 2002). These interventions help renal patients to cope with the mental health consequences that are often associated with a diagnosis of CKD (Beder, 1999; Furr, 1998; Hailey et al., 2001; Illiĉ, Djordjeviĉ, & Stefanoviĉ, 1996; Kimmel, 1992; Kimmel, Weihs, & Peterson, 1993; Peterson et al., 1991), and they help to promote long-term compliance with treatment. Studies have demonstrated how social work interventions such as counseling and education have a positive effect on patients' psychological well-being and on their psychosocial adjustment (Beder, 1999; Dobrof et al., 2001).

Social work services, as described in the original 1976 Medicare mandate (Department of Health, Education, and Welfare, 1976) consist primarily of counseling-based activities. These activities are becoming more difficult to provide, in part because of the workload associated with large patient caseloads, nonclinical duties imposed by employers, and the complex medical and mental health needs of patients. According to the Medicare mandate:

> Social services are provided to patients and their families and are directed at supporting and maximizing the social functioning and adjustment of the patient. . . . The qualified social worker is responsible for conducting psychosocial evaluations, participating in team review of patient progress and recommending changes in treatment based on the patient's current psychosocial needs, providing casework and groupwork services to patients and their families in dealing with the special problems associated with ESRD [End Stage Renal Disease], and identifying community social agencies and other resources and assisting patients and families to utilize them. (Sec. 405.2163b)

In order to assist patients in accordance with this Medicare mandate, social workers must have adequate time and resources to provide those patients with psychosocial support services. Social work practitioners who work in dialysis settings possess specialized knowledge of the psychological and emotional aspects of disease and illness (Callahan, 1998; Rosen, 1999). But this specialized knowledge is not being used to full advantage when their day-to-day responsibilities include doing numerous clerical tasks, arranging patient transportation and travel, dealing with billing issues, and verifying patients' insurance.

Emotional Exhaustion and Workload

Studies of emotional exhaustion began with Maslach's (1982) path-breaking research on burnout. In this research, Maslach devised a model of burnout that is made up of three parts: emotional exhaustion, depersonalization, and reduced personal accomplishment. The first component of the burnout model, emotional exhaustion, consists of being in a chronic state of feeling emotionally drained, being physically fatigued, and having depleted emotional resources. The second component, depersonalization, is characterized by an inability to form interpersonal connections with others, such as patients, clients and coworkers. The third component, reduced personal accomplishment, includes negative self-evaluations in which a person feels that she or he is incompetent and ineffective. Recent empirical investigations have shown that emotional exhaustion is a significant predictor of job performance (Wright & Cropanzano, 1998) and commitment to an organization (Cropanzano, Rupp, & Byrne, 2003).

In addition to feeling emotionally exhausted as a result of one's job, a person's perception of her or his workload can also contribute to negative occupational health outcomes. According to Spector and Jex (1998), "workload can be measured in terms of the number of hours worked, level of production, and even the mental demands of the work being performed" (p. 358). Spector and Jex developed a brief workload measure—the Quantitative Workload Inventory (QWI)—that can be used to assess workload in terms of pace and volume. In their meta-analysis of 18 studies to demonstrate the validity of the QWI, Spector and Jex reported that the QWI is strongly correlated with the experience of role conflict and frustration in one's job. As the professional role and responsibilities of social workers begin to be more clearly defined in terms of patient caseloads, involvement in nonclinical activities, and job satisfaction (see Merighi & Ehlebracht, 2004a, 2004b, 2004c), the influence of emotional exhaustion and workload on renal social workers' professional practice and occupational well-being merit further investigation.

Hypotheses

This study examined the influence of emotional exhaustion and workload on renal social work practice. Four research hypotheses were developed to test the relation of these outcome measures to facility classification and three specific job activities.

Hypothesis 1: There will be a difference in the level of emotional exhaustion reported by full- time (35 or more hours per week) and part-time (20-34 hours per week) social workers by facility classification (private for-profit, private nonprofit, public).

Hypothesis 2: There will be a difference in the workload level reported by full- and part-time social workers by facility classification.

Hypothesis 3: For full- and part-time renal social workers, there will be:
  a) a negative relation between level of involvement in clinical activities and emotional exhaustion after controlling for the effect of caseload size;
  b) a positive relation between level of involvement in clerical activities and emotional exhaustion after controlling for the effect of caseload size; and
  c) a positive relation between level of involvement in insurance activities and emotional exhaustion after controlling for the effect of caseload size.

Hypothesis 4: For full- and part-time renal social workers, there will be:
  a) a negative relation between level of involvement in clinical activities and workload level after controlling for the effect of caseload size;
  b) a positive relation between level of involvement in clerical activities and workload level after controlling for the effect of caseload size;
  c) a positive relation between level of involvement in insurance activities and workload level after controlling for the effect of caseload size.

METHODS

Dillman's (1978) total design method was used to conduct a mail survey of renal social workers employed in dialysis units throughout the United States and the US territories.

Respondents

A sample of 809 respondents from all 50 states, American Samoa and Puerto Rico was used for this study. The respondents were obtained by generating a list of all dialysis units that were in operation throughout the United States in October 2002 (N = 4,199), and selecting a stratified random sample of 1,500 units. The strata used to develop the sampling frame consisted of end stage renal disease (ESRD) network number and zip code. The overall response rate was 54.4 percent, after adjusting for surveys that were returned due to incorrect address information (n = 7), or social workers who called the authors to indicate that they worked at more than one dialysis unit and received the survey at more than one location (n = 8).

The sample consisted of 80.0 percent European Americans, 8.9 percent African Americans, 4.4 percent Hispanics/Latinos, 1.8 percent Asians/Pacific Islanders, and 4.9 percent Mixed Heritage/Other. The respondents' ages ranged from 23 to 72 years (M = 44.9, SD = 10.9), and their social work practice experience ranged from 1 month to 35 years in nephrology settings (M = 6.4 years, SD = 5.9) and from 5 months to 45 years in all practice settings (M = 14.9 years, SD = 9.3). The majority of the respondents were women (87.1 percent), had a master's degree in social work (95.4 percent), had a social work license (77.7 percent), worked for private, for-profit dialysis facilities (72.2 percent), and earned $40,000-$49,999 per year (37.5 percent). The length of time with their current employer ranged from 1 month to 31 years (M = 5.4 years, SD = 5.5), and approximately one half of the study respondents (52.5 percent) worked for only one dialysis unit (31.7 percent worked for two units, 11.4 percent worked for three units, and 4.4 percent worked for four or more units). All participants volunteered to participate and were treated in accordance with the guidelines on evaluation and research described in the National Association of Social Workers (NASW) Code of Ethics (NASW, 1999).

Measures

A 245-item Nephrology Social Worker Job Survey was used to evaluate renal social work practice in three broad domains: (1) professional development and training, (2) dialysis unit issues, and (3) patient care. Each domain contained open- and closed-ended questions that assessed the job-related attitudes and behaviors of the respondent. Two of the outcome measures used in this study, i.e., emotional exhaustion and workload, are described below.

Job-Related Emotional Exhaustion (JEE). The JEE was used to measure how often respondents felt "used up" as a result of their work (Wharton, 1993). This measure consists of six items that are rated on a seven-point scale, from zero (never felt this way while at work) to six (felt this way every day). Sample items include "I felt emotionally drained from my work," "I feel frustrated by my job," and "I feel I'm working too hard on my job." The JEE total score ranges from 0 to 36, with high scores being indicative of a high level of emotional exhaustion. A mean score of 14.8 (SD = 7.7) was obtained from a study of 622 hospital and bank employees (Wharton, 1993). Cronbach's alpha for the current study was 0.91.

Quantitative Workload Inventory (QWI). The QWI was used to measure the pace and volume of work associated with the respondent's job (Spector & Jex, 1998). This measure consists of five items that are coded on a five-point scale, from one (less than once per month or never) to five (several times per day). Sample items include "How often does your job require you to work very fast," "How often is there a great deal to be done," and "How often do you have more work than you can do well?" The QWI total score ranges from 5 to 25, with high scores corresponding to high workload level. A weighted mean score of 16.5 (SD = 3.4) was obtained from 15 studies with 3,728 participants (Spector, n.d.). Cronbach's alpha for the current study was 0.90.

Data Collection Procedure

The total design method uses a systematic approach that maximizes the response rate for mail surveys. For this study, the data collection procedure consisted of five sequential steps: (1) sending an introductory letter, addressed to "Renal Social Worker," to 1,500 randomly selected dialysis units; (2) sending a study packet that contained an implied consent letter, the Nephrology Social Worker Job Survey, and a postage-paid return envelope; (3) sending a reminder postcard; (4) resending the study packet to all 1,500 dialysis units; and (5) sending a thank-you postcard. To maintain the respondents' anonymity, study packets were resent to all 1,500 dialysis units and tracking numbers were not used on the surveys. Study respondents were asked to complete the survey and return it in the prepaid envelope only if they agreed to the conditions of the study as outlined in the implied consent letter. No compensation or incentives were offered in exchange for completing the survey.

Statistical Analyses

For the purpose of this study, a part-time employee was defined as a person who worked between 20 and 34 hours per week, and a full-time employee was defined as a person who worked 35 hours or more per week. Work activity data for social workers who reported working fewer than 20 hours per week were removed from this study. One-way analysis of variance was used to test for differences in the social workers' reported level of emotional exhaustion and workload by facility classification (private for-profit, private nonprofit, and public) and employment status. Partial correlations were computed to examine the association between the social workers' reported level of emotional exhaustion and workload and their level of involvement in specific job activities, controlling for the effect of patient caseload size. In this study, social workers reported the number of hours they typically spent per week in nine specific work domains: counseling, psychosocial assessment, insurance-related tasks, patient billing, clerical tasks, patient charting, patient education, arranging patient travel and unit management. These hourly data were converted to a percentage of total time worked per week.

RESULTS

Emotional Exhaustion and Workload by Facility Classification: Hypotheses 1 and 2

Hypotheses 1 and 2 predicted that both part-time and full-time social workers would report different levels of emotional exhaustion and workload based on how their facility was classified. These predictions were not supported. Although workers in public facilities, in general, reported higher levels of emotional exhaustion and workload as compared to their counterparts in private facilities, the main effects for the facility comparisons were not significant. Table 1 summarizes emotional exhaustion and workload scores by facility classification.

Table 1. Emotional Exhaustion and Workload Scores by Facility Classification and Employment Status *(N=385)*

	20-34 hours/week ***M (SD), n*** **= 307**	**35+ hours/week** ***M (SD), n*** **= 278**
Facility Classification	**Emotional Exhaustion**	
Private, for-profit	15.0 (7.8)	15.9 (9.0)
Private, nonprofit	14.7 (7.9)	16.1 (8.1)
Public	14.8 (6.4)	19.4 (8.7)
	Workload Scores	
Private, for-profit	17.8 (4.9)	18.4 (4.4)
Private, nonprofit	17.1 (4.7)	18.9 (4.5)
Public	19.2 (4.2)	19.9 (5.4)

Emotional Exhaustion and Job Activities: Hypothesis 3

Partial correlations were computed to examine the association between emotional exhaustion and nine job activities, while controlling for the effect of patient caseload size. All three predictions for Hypothesis 3 were supported for both full-time and part-time workers. Table 2 provides a summary of the correlations between all nine work activities and emotional exhaustion by employment status. As predicted, full- and part-time social workers who spent more time doing counseling reported less emotional exhaustion, and those who spent more time doing insurance and clerical activities reported more emotional exhaustion. Also, part-time employees who spent more time doing psychosocial assessments and providing patient education felt less emotionally exhausted, and those who spent more time doing patient billing felt more emotionally exhausted. For full-time employees, the more a social worker was involved in patient education, the less she or he reported feeling emotionally exhausted.

Table 2. Partial Correlations Between Level of Job Activity Involvement Per Week and Emotional Exhaustion by Employment Status, Controlling for Patient Caseload Size *(N=562)*

	Emotional Exhaustion	
Activity	**20-34 hours/week** **n = 298**	**35+ hours/week** **n = 264**
Counseling	-.291**	-.310**
Psychosocial assessment	-.137*	-.022
Insurance	.139*	.217**
Patient billing	.151*	.007
Clerical tasks	.215**	.221**
Patient charting	-.108	-.052
Patient education	-.215**	.189**
Patient travel	.091	.071
Unit management	.111	-.028

* p < .01, one-tailed.
** p < .001, one-tailed.

Workload and Job Activities: Hypothesis 4

Only one of the three predictions for Hypothesis 4 was supported for both full- and part-time employees using partial correlations that held patient caseload size constant. Specifically, there was a negative relationship between providing counseling services and workload level—that is, as involvement in counseling activities increased, the level of self-reported workload level decreased. No relationship was established between performing clerical activities and self-reported workload level. In regard to insurance activities, a positive relationship was found between the time spent assisting patients with insurance issues and workload for only part-time employees. In addition, part-time employees who have a higher level of involvement in doing psychosocial assessments and providing patient education reported a lower workload level. Table 3 provides a summary of the correlations between all nine work activities and workload by employment status.

Table 3. Partial Correlations Between Level of Job Activity Involvement Per Week and Workload by Employment Status, Controlling for Patient Caseload Size *(N=562)*

	Workload	
Activity	**20-34 hours/week n = 298**	**35+ hours/week n = 264**
Counseling	-.204**	-.181*
Psychosocial assessment	-.156*	-.007
Insurance	.198**	.069
Patient billing	.089	.012
Clerical tasks	.089	.131
Patient charting	-.062	-.053
Patient education	-.151*	-.102
Patient travel	.039	.114
Unit management	.079	.024

* p < .01, one-tailed.
** p < .001, one-tailed.

Discussion

Few studies have examined the emotional exhaustion and workload demands of social workers in health care settings. The current study provides a preliminary examination of renal social workers who comprise a specific area of social work practice in health care, and the factors associated with experiencing high or low levels of emotional exhaustion and workload. In this study we found no differences in self-reported emotional exhaustion or workload based on the type of facility that employed the social worker—i.e., private for-profit, private nonprofit, and public (see Hypotheses 1 and 2). Although workload demands and emotional exhaustion were slightly greater for social workers employed in public dialysis facilities, these differences were not sufficient to reach statistical significance. Future research needs to examine potential factors that may be unique to public facilities and that may cause social workers to experience negative health consequences related to their job.

Some of the most noteworthy findings in this study consisted of the associations between the social workers' emotional exhaustion (Hypothesis 3), workload (Hypothesis 4), and three specific job activities—providing counseling to patients and family members, performing clerical tasks, and assisting patients with insurance issues. For full- and part-time renal social workers, as the time spent counseling or providing education increased, feelings of emotional exhaustion decreased. These relationships may be indicative of the fact that providing education and direct counseling to patients and family members are activities that are commensurate with the professional training and education of master's-level social workers. There were also significant positive correlations between emotional exhaustion and the amount of time full- and part-time social workers spent doing insurance and clerical tasks. These tasks are not central to the education and training of professional social workers, and they may cause social workers to perceive their job as emotionally draining. Given the adverse outcome associated with performing insurance and clerical tasks at a high rate, additional studies are needed to explore how extensive involvement in nonclinical tasks is related to job attrition.

The association between workload and job activities varied greatly for part- and full-time workers (Hypothesis 4). For social workers in both employment status groups, an increase in time spent doing counseling was associated with a decrease in their workload level. Contrary to our predictions, performing clerical tasks was not significantly related to workload level for full- and part-time employees. Further, only part-time workers reported a positive relation between involvement in insurance activities and assessment of workload. This outcome may be attributed to the greater amount of time that full-time social workers have to pursue and solve patient insurance problems, while part-time workers may experience constraints due to their work schedule.

The study findings provide a solid foundation upon which social workers can advocate to change current dialysis unit policies, procedures and practices that undermine their occupational well-being. These advocacy efforts are central to maintaining a well-trained and healthy workforce, and they can be used to inform revisions to the Federal Register so that social workers responsibilities on dialysis units will be in accordance with their professional training and education. One area in need of additional research is the effect of patient acuity and comorbidities on social workers' assessments of their workload and management of emotions in the workplace.

Summary

This investigation explored emotional exhaustion and workload demands in the context of renal social work practice. The following is a summary of findings for each of the four research hypotheses tested in this study:

- *Hypothesis 1 (not supported).* There was no significant difference in the level of emotional exhaustion reported by full- or part-time social workers who were employed in private for-profit, private nonprofit, or public dialysis facilities.
- *Hypothesis 2 (not supported).* There was no significant difference in the level of workload reported by full- or part-time social workers who were employed in private for-profit, private nonprofit, or public dialysis facilities.
- Hypothesis 3 (supported). For full- and part-time social employees: (a) the more time social workers spent on clinical activities, the less they reported feeling emotionally exhausted; (b) the more time social workers spent on clerical activities, the more they reported feeling emotionally exhausted; and (c) the more time social workers spent on insurance activities, the more they reported feeling emotionally exhausted.
- *Hypothesis 4 (partially supported).* For full- and part-time social employees, the more time social workers spent on clinical activities, the lower they rated their overall workload. For part-time workers, the more time they spent on insurance activities, the higher they rated their overall workload. No significant correlations were found between workload and performing clerical activities for full- or part-time workers.

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Predialysis Anxiety: What are the Concerns of Patients?

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The presence and intensity of predialysis anxiety was investigated. Forty-four people who attended a predialysis educational class were evaluated for anxiety before and after attending the class. The majority of participants reported having moderate anxiety. African Americans and women reported higher levels. Participants were most concerned about their level of functionality once they initiate dialysis. However, gender differences were noted with regard to the specific types of concerns. No statistically significant correlation was found between anxiety and educational level or anxiety and age. The class did appear to reduce the level of anxiety for most participants. The majority of those who did not believe that the class reduced their anxiety were women. Further investigation regarding the format of predialysis education is recommended along with more specific tailoring to individual learning needs.

Key Words: *Anxiety, Predialysis, Education and Assessment*

PREDIALYSIS ANXIETY: WHAT ARE THE CONCERNS OF PATIENTS?

The presence of psychiatric symptoms post-initiation of dialysis is well documented within the research literature (Mazella, 2004; Zimmerman, Figueiredo & Fonseca, 2001; Estrada & Hunt, 1998). Once a person begins dialysis they usually have frequent contact with medical professionals who can assist in the assessment and treatment of these ailments. The repetitive nature of this contact can lend itself to a person's adjustment to treatment through education, social support from other patients, relationships with staff and other facets. However, there is limited research regarding the presence of anxiety and specific patient concerns in the predialysis period. This can potentially be a very stressful, and possibly lengthy, time for someone who knows that they are near the end stage of renal disease. The proverbial fear of the unknown, concerns about finances, personal functional decline and worry about death are but a few of the possible anxiety inducing factors that a person might experience before starting dialysis. Depression has historically been more of a primary focus than anxiety in the research literature regarding dialysis. However, some studies have noted it to be more prevalent in the dialysis population than depression (Lye, Chan, Leong & van der Straaten, 1997). Predialysis anxiety has also been correlated with poorer ratings of ones' health (Klang, Björvell, Berglund, Sundstedt & Clyne, 1998).

Predialysis education has become an important part of many clinic programs and there are numerous ways in which it is provided. Research has been conducted to determine if it can positively influence treatment. Predialysis education has been found to extend the time to treatment initiation and to reduce the number of emergent starts (Devins, Mendelssohn, Barré & Binik, 2003; Levin et al., 1997). It has also been noted to facilitate continued employment and aid in modality selection (Golper, 2001; Klang, Björvell & Clyne, 1999). Some clinics use formal classroom formats to educate patients while others use one-to-one meetings. Federal legislative efforts have been made to make it uniformly available, such as through the proposed Kidney Disease Educational Benefits Act of 2003 § (Senate Bill S. 1114). Overall, the collective body of investigative literature tends to show that predialysis education is beneficial.

Research Objective

The research presented here sought to answer four basic questions. First, what is the prevalence and level of anxiety? Second, are there demographic groups with higher levels? Third, what are the primary anxiety inducing concerns? Fourth, can a single educational session reduce anxiety? By answering these questions social workers will have a better understanding of the causes and nature of anxiety within the pre-dialysis population. This can better facilitate psychological assessment and treatment options, which will in turn improve the quality of life for those who have not yet started dialysis.

Design and Method

An informal inquiry was made with several people on dialysis and various clinic staff. They were asked to list the types of concerns that they often noted in the predialysis period. The 16 most common responses were obtained and placed into a questionnaire format.

Through the questionnaire respondents were asked to report if they were experiencing any of the 16 concerns. It also asked whether or not they were currently experiencing anxiety about starting dialysis and, if so, to denote their level of anxiety through the use of a seven-point Likert Scale. (See Appendix A.)

The questionnaire was given to 53 people who attended a predialysis educational class. The class was offered twice per month over the span of one year at one clinic. The people who attended had been referred to the class by their physician because they were expected to begin dialysis within six to twelve months. This represented a sample of convenience since they were not randomly selected. The data presented here is an aggregate of their responses. They were informed orally and in writing that participation in completing the questionnaire was voluntary and that their responses would be anonymous. It was also relayed to them that whether or not they participated, they would still receive all of the content of the class. The questionnaire was administered before the class started and 44 people completed it, resulting in a response rate of 83%.

The class was then held and it lasted approximately three hours. Educational instruction came from several different sources. First, the attendees watched a 30-minute videotape that provided basic information regarding the various dialysis modalities and renal transplantation. The clinic social worker then made a presentation and discussed general insurance issues, Medicare, transplantation, transportation and travel. The clinic dietitian discussed aspects of the renal diet and the differences that could be expected which each modality. The clinic nurse presented the various dialysis accesses and technical aspects of each modality. A question and answer period was provided by each staff person at the end of their presentation. A tour was then given of the facility. At the end of the class participants were administered a second brief questionnaire. They were asked to report whether or not the information provided to them had reduced their anxiety, and to rate their post-class anxiety level. Demographic data was collected on the questionnaires. The participants had an average age of 64 years and a high-school graduate level of education. There were slightly more men than women, and nearly 60% were African American. Half were married and half were single, divorced or widowed.

RESULTS

When asked if they were experiencing anxiety about having to start dialysis, 77% of women and 74% of men responded yes. The average level of anxiety was 3.6 on the seven-point Likert Scale, placing it near the moderate range. The average for women was 4.1 and for men it was 3.2. Higher levels were reported by women and African Americans.

Table 1

Average Level of Predialysis Anxiety

African-American Females:	4.4
Caucasian Females:	4.0
African-American Males:	3.5
Caucasian Males:	2.8

Using a seven-point Likert Scale with
1 = Slightly anxious and 7 = Severely anxious

(Among those reporting the presence of anxiety)

A Spearman Rank Correlation was performed to determine whether there was a connection between age and anxiety level as well as years of education and anxiety level. Both tests showed insignificant results. Age and anxiety level had a correlational value of rs = .08 while years of education and age had a value of rs = -.06.

The five most common concerns about having to start dialysis, and the percentage of participants noting them, were: I might not be able to care for myself (45%), Not being able to perform my usual daily tasks (43%), It will make me feel ill (38%), Dialysis will take up a lot of my time (34%), Not having enough money to pay my bills (31%) and Cost of dialysis (31%). Analysis of the most common concerns based on gender showed notable differences. The main concerns among women were: I might not be able to care for myself (57%) followed by It will make me feel ill (47%) and Dialysis will take up a lot of my time (42%). For men, the main concerns were: Not being able to perform my usual daily tasks (50%), followed by Not having enough money to pay my bills (37%) and It will make me feel ill (37%).

When asked if they believed that the educational class had reduced their anxiety, 70% of participants responded yes. The majority of those who responded negatively were women. When asked to rate their level of anxiety after the class, the level had dropped to an average of 2.8 on the seven-point Likert Scale placing it at the 'somewhat anxious' level. For women, the average was reduced to 3.2 and for men it was 2.7.

DISCUSSION

Three-fourths of participants reported having anxiety about having to start dialysis. Gender did not appear to have much of an influence on the presence of this symptom, but it did on the level of anxiety. Whether this represents an under-reporting bias by the male participants is unknown. Race appeared to be an important factor with regard to the level of anxiety, with African American women and men having higher levels than Caucasians. It is noted that nearly 67% of the people on dialysis in the End-Stage Renal Disease Network region in which this research was conducted are African American (National Institutes of Health, 2002). A higher prevalence of dialysis within the African American population might lead to more individual exposure to it, in turn causing more anxiety about having to start it. This would be supported by the fact that the African American participants in this research reported a significantly higher degree of knowledge about dialysis as compared to the Caucasians prior to taking the educational class.

Globally, participants were most concerned about their functionality after they begin dialysis treatment. They were worried about not being able to care for themselves, not being able to perform daily tasks and feeling ill. However, women were more concerned about not being able to care for themselves while men were more concerned about not being able to perform daily tasks. Concerns regarding how dialysis might impact relationships with friends was low, with only two participants endorsing this. None of the participants reported dialysis as being a potential problem with their spousal relationship. Concerns regarding death and physical scarring were also low, which was somewhat of an unexpected finding.

Provision of education reduced the level of anxiety across all genders and races within the participating sample. Similar findings have been found with educational programs for people who are about to undergo treatment for cancer (Thomas, Daly, Perryman & Stockton, 2000; McQuellon, Wells, Hoffman, Craven, Russell, Cruz, Hurt, DeChatelet, Andrykowski & Savage, 1998). Various methods have been used to prepare people with cancer for the therapy that they are about to receive, and education seems to reduce their anxiety as well as increase satisfaction with treatment. There is always a risk that the provision of information might actually increase the level of anxiety for some people. This was noted by 5% of the cancer patients in the study by Thomas, Daly, Perryman & Stockton (2000) but overall the majority of participants felt that it was beneficial.

In this study, women were less likely to report that the class reduced their anxiety. Therefore, it is possible that other formats might be better suited to their needs. This knowledge will hopefully allow for tailoring of predialysis education to the individual. Though most research seems to show a benefit from education, the way in which it is presented is likely to be a more important variable than just its provision. Gender and racial differences regarding the main concerns about starting dialysis should be taken into consideration since it appears that predialysis concerns are not homogenous. Other formats for predialysis education, such as one-to-one sessions or those that use nothing but videotaped presentations, will need to be further investigated to determine if they also decrease anxiety and if they are better able to do so. There are numerous other factors that need to be examined with regard to anxiety. The concerns of partners, family members and friends need further investigation since chronic illness affects the whole family. Patients' children and parents are also likely to have a unique set of anxiety inducing concerns. Overall, assessing and treating anxiety only after treatment has been initiated is shortsighted and overlooks the predialysis period.

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APPENDIX A

Potential Concerns About Having to Start Dialysis
What concerns do you have about starting dialysis? (Check all that apply. You may choose more than one.)

___ Not being able to work or go to school.
___ Not being able to do my usual daily tasks such as shopping, driving, hobbies, etc.
___ Cost of dialysis treatment.
___ Not having enough money to pay my bills.
___ It will require more surgery.
___ Dialysis will take up a lot of my time.
___ It will make me feel ill.
___ Pain of the dialysis treatment.
___ My friends might not want to continue being my friends.
___ My husband/wife/companion might leave me.
___ Dialysis will affect my ability to think or make decisions.
___ Dialysis will change the way I look or how others will look at me.
___ Starting dialysis means that my health is getting worse.
___ Dialysis will scar or disfigure me.
___ I might die.
___ I might not be able to care for myself.

Transformations: A Phenomenological Investigation into the Life-World of Home Haemodialysis

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With a growth in home-care, and increased funding for dialysis, there is a need for the field of Social Work to understand the life-world of people who experience home haemodialysis technology (HDDT). Given little research has focused on the lived-experiences of this population (Nagle, 1995), an exploratory qualitative study was employed (Strauss & Corbin, 1998). The study investigated the embodied life-world experiences of this population using phenomenological methods (Kvale, 1996; van Manen, 1997). The data was collected and analyzed in terms of the four basic phenomenological categories of lived-time, lived-body, lived-spatiality, lived-relations with others and self (van Manen, 1997). A purposive sample of four was selected, and interviewed using semi-structured interviews, with each participant experiencing various lengths of HHDT. The findings revealed that their life-world had been transformed by their experience of HHDT. In particular, it was documented how participants' adoption of medical practice and discourse has impacted the lived-body, suggesting a need to adopt a plain language or holistic medical discourse practice approach for communication with patients which supports bodily-integrity and sovereignty. Additional findings centered on the incorporation of HHDT into the family unit, and how HHDT may present a health care access barrier to those without homes. Moreover, aspects of the transformation of the home into a hospital were highlighted. Finally, it is suggested that social assessment should consider the patient and family's experience of the dialysis machine.

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***Key words**: Home dialysis, life-world, embodiment, phenomenology, home care, haemodialysis, qualitative research, renal social work*

BACKGROUND

Haemodialysis is the medical treatment for people who live with End Stage Renal Disease. As such, treatments are usually 3 times per week for 3 to 5 hours for each treatment, but this may vary. Treatment may happen at the home or in a hospital. Nocturnal home haemodialysis dialysis differs from daytime dialysis in that the treatments are usually 6 nights per week. The reasons for choosing this topic as an area for study are at first personal. During an interview with a person who was receiving haemodialysis in her home, I was both touched and intrigued by the way she talked about her experience of home haemodialysis technology. In doing so she hinted at a personal and embodied relation with her dialysis machine. As such, this article presents findings from my Master of Social Work thesis (Giles, 2001), a phenomenological study of four people who live with home haemodialysis technology (HHDT).

RATIONALE

Canadian provincial leaders have pledged to increase funding for home care and new health care technologies, such as dialysis machines (Government of Canada Privy Council Office: Intergovernmental Affairs, 2000). These factors when considered along with Nose's (2000) suggestion that home haemodialysis is both low cost and safe, add up to a trend toward an increase in the use of home haemodialysis treatment for people with end stage renal disease (Blagg, 1996; Boyle, 2000). Thus, increasing levels of technological advancement in health care, combined with a shift to shorter hospital stays and increased reliance on home care (Egan & Kadushin, 1999), means patients will have less face-to-face interaction with health care providers than in the traditional hospital settings over the course of their treatment. One can therefore predict that the trajectory of this change in health care policy will mean for patients both an increased involvement with, and reliance on, medical technology in the their home setting.

With the role of social work in medicine long established (Erickson & Erickson, 1989; Roberts, 1998), it follows that medical social work in general, and nephrological social work in particular, will be impacted by the changes in the advancement of medical technology and health care policy. Medical technology in the context of a hospital setting is familiar and expected by patients and social workers alike. Modern medical machinery in the home, however, is a newer development. This development has led social workers to study certain aspects of home care such as the policies and procedures developed by home care agencies (Kaye & Davitt; 1996). Arguing that home care is the fastest growing sector in health care, Kaye and Davitt (1999) have produced a comprehensive study of home care from a social work perspective. However, its section on patients' experiences is based on a patient satisfaction questionnaire, and so fails to yield substantive patient centered experiential data. Consequently, from a subjective and qualitative perspective, there is still more to be understood about the patient's life-world from within the context of home based medical technology. Thus with a greater understanding of patients' subjective experiences of HHDT, social workers will be better situated to plan interventions which specifically take into account the personal and subjective experiences of people who live with HHDT.

LITERATURE REVIEW

To date most research on HHDT has focused on the patient within the context of the medical model of illness. From this starting point, others have expanded what was once the traditional focus of medical treatment, the patient's physiologic response, to include what has now become the new and complimentary variable: that of the patient's psychosocial response to illness (Sheriden, 1977; Mathews, 1978; Petersen, 1982, 1984, 1985; Courts, 2000). In this way the construct of response, which implies a linear and causal effect pattern, has been re-deployed from medical physiology into the area of patient experiences. This redeployment supports the medical model of illness suggests that psychosocial experiences can be quantified in the same way that physiological responses can be quantified.

Other areas of research on this topic that support the medical model of illness, and resultant treatment regime, have been in the area of the legitimacy and importance of the health care team in the provision of HHDT treatment (Palmer, Canzona & Wai, 1982; Athcherson, 1978), and on measures to improve patients' compliance and adherence to medical treatment (Witenberg, Blanchard, McCoy, Suls et al., 1983). The result of this research on the patients from within a quantitative medical and biological perspective is that there is to date little available research on the patient's lived-experience and understanding of illness (Wright & Kirby, 1999). This review of the literature supports Nagle's (1995) claim that to date the research on haemodialysis has focussed on physiologic and psychosocial responses to illness. At the time of study, other than by Nagle (1995), there has been no reported research on the life-world of people who receive home haemodialysis. Nagle's (1995) research, noting this gap, and employing philosophical hermeneutic research methods, focussed on the meaning of technology experienced by those who received haemodialysis treatment for end-stage renal disease. Specifically, Nagle investigated to what extent their experience revealed the embodying, or experiential incorporation of medical technologies, into the subjective experience of their bodies. Utilizing semi-structured interviews, she concluded that the meaning of technology for the participants in her study depicted a continuing struggle against objectification and disembodiment in the context of illness care. Interestingly, despite the pervasive and relentless threat to embodiment posed by the haemodialysis technology of illness care, "the participants remained embodied." This objectification or threat of disembodiment, she argues, is supported by the mind-body dualism which medical science is predicated on, where the focus on the treatment of the physiological body overlooks the totality of the human experience. It is no surprise then the social work practice tradition has also failed to acknowledge the importance of bodily-knowledge (Peile, 1998; Tangenberg, Kathleen M., & Kemp, Susan, 2002). The limitations of Nagle's (1995) methodology from a qualitative perspective, are that in using the hermeneutic circle of reflection, there is a tendency to essentialize or condense the experiences of all the participants until a final constitutive pattern is arrived, which thereby gives voice to the central experience of the participants. In this way individual differences are left out of the study.

THEORETICAL FRAMEWORK

Given that there was a dearth of research on the topic, a qualitative exploratory study was called for (Strauss & Corbin, 1998; Schriver, 1998; Singleton & Straits, 1999). Moreover, where context and value of the setting are critical, such as the home environment proposed here, in order to gain a deeper understanding of the phenomena, qualitative methods are essential (Toombs, 1988; Moustakas, 1990; Marshal & Rossman, 1995; van Manen, 1997). In particular, phenomenological research is exceptionally well suited for investigating the lived-experience (van Manen, 1997). As such, phenomenology focuses on life-experience, precise descriptions, a bracketing of foreknowledge and a search for essential meanings (Kvale, 1996). If we grasp the lived-body in terms of being-in-the-world, it can help us understand the profound sense of disorder which is manifested in the experience of illness; for illness is experienced more as breakdown of the lived "world" than a break down of the "biological" body (Toombs; 1988).

In the context of recent writing on medicine and philosophy, the view that a humanistic perspective is required in medicine is supported by Zaner (1990) and Bevan (2000). Zaner suggests that medicine needs to be reconceived so as to provide an appropriate emphasis on the patient's experience and understanding of illness, and phenomenology provides a framework for such an emphasis.

The concept of lived-experience (van Manen,1997) is helpful here as a way of focussing people's experiences by contrasting subjectivity against objectivity. For example, the experience lived-time can be markedly different than objective time, where an 'objective' minute can feel like a 'subjective' eternity. The idea that time can go fast or slow is a good example of how living time subjectively can differ from the objective measurement of it. In this way the various lived-experiences such as lived-timed or lived-body can be said to add up to our total subjective experiences, which can be referred to as the life-world (van Manen, 1997).

The distinction between objective physiological bodies and phenomenal bodies are central for existential analysis of any human phenomenon (Leyland, 1995). As such, embodiment theory represents the phenomenological focus on the body as a unified potential for action. For when Merleau-Ponty (1962/1999) writes the "world is not what I think, but what I live through," he means that the body as lived-experience is where the analysis of phenomena must begin. This paradigm of understanding, that the body is central, has been adopted by many researchers, thus contributing to the subsequent growth in the area of embodiment research. While a substantial amount of research exists in the area of body image, other researchers are pointing to the idea that bodies are ways of knowing, and that they are social products which may lead to personal and social change (Jones, 1993; Weiss, 1999). Also acknowledged are the threats to bodily-integrity coming from social process that in turn may lead to a process of bodily-reconstruction (Gattuso, 1996). The argument that bodies are susceptible to social forces (Synott, 1992), is helpful to our understanding of body and embodied self, because it challenges the idea that bodies are merely biological.

RESEARCH QUESTIONS

In an attempt to overcome the limitations of Nagle's (1995) study, and following her suggestion that the "notion of threatened embodiment should be explored within different illness and contextual circumstances," this study investigated and explored the embodied life-world experiences of four people with end-stage renal disease. Specifically, it asked the question, what it is like to be-in-the-world with a home haemodialysis machine? Moreover, within this context is the embodied-self preserved, transformed or something else?

METHOD AND PROCEDURES

Sample

A purposive sample of four adults were selected who had a range of lengths and familiarity with home haemodialysis. All participants came from a large Canadian urban hospital and were selected by the nursing team. All participants spoke English, and were medically stable enough to participate in the study. The four participants included one adult male person in the beginning of nocturnal home haemodialysis technology training (NHHDT), one adult male person in the second week of NHHDT training, one adult male person with a year of NHHDT, and another adult female person with a year of daytime home haemodialysis technology experience (DHDDT). As this was an exploratory study no attempt was made to capture specific participants with regard to age, ethnicity, sexual orientation or socioeconomic status.

Data Collection and Analysis

The hospital's research ethics board approved this study. Interviews utilized a semi-structured interview guide, were tape-recorded, and transcribed by a professional transcriber. Each interview was read and reread in its entirety, one interview at a time. This produced a list of themes from each case, which were established and sorted under one of the four basic existential themes. The next step was to separate or subjectively highlight the essential themes from the incidental ones, as merely condensing the data would not suffice, and the inclusion of all themes was beyond the scope of the original study and in particular this presentation of the thesis. This method of separating incidental from essential themes is a subjective method and is perhaps the most controversial element in phenomenological human sciences. From here the central themes from all of the cases were then considered together, allowing the themes to naturally group together with each other into new cross-case or inter-case groupings. The result of the inter-case analysis allowed for new interpretations and themes to emerge and develop.

Validity

Participants were interviewed in an environment of their choice, increasing thereby the contextual validity of the interviews. During each interview clarification was sought, enabling the confirmation of whether or not the correct understanding of the experiences they were to describe was attained. By having two one-hour interviews with each participant, over a period of two weeks, an increased sense of prolonged engagement (Lincoln & Guba, 1985) was attained.

HIGHLIGHTS OF RESEARCH FINDINGS

Lived-Time

Time Is the Prescription: The Embodiment of Time

This cluster of themes saw time being experienced as commodity or object which was embodied, allowing for the ownership of it to become a site for resistance. One participant experienced time being broken into fragments based on the dialysis treatment schedules of the amount of time per day, and days per week. In this way, time itself was the prescription. As the time was increased it produced a feeling that the person himself was being stretched inch by inch and finally an experiential increasing of himself.

> "Well I was here on the floor and came in and they hooked me up and put me on it for two hours. And at that time the two hours wasn't too much of a problem. And then they gradually increased me to four hours and that wasn't such a [. . .] and then five hours. And that was three times a week and then to every day for 3 1/2 hours. And the more time as they started to you know increase the time, it started to get a little bit bothersome . . ."

Experiencing time as objective blocks, which were prescribed, allowed for time as something to be owned. The result was that there was a dispute as to who actually owned it, the participant, or the nurses. This allowed for time to be a site of resistance for him. Time as a commodity or object was also experienced by another participant who talked about the heaviness of carrying time between treatments.

> "So I felt if I had been you know carrying my time for several days then I would try to make it up."

Lived-Space

Isolation, Intrusions, Sickness, Voyeurism, and Bonding: Living the Hospital Spatiality

The participants talked about their experiences of the varying hospital room configurations they experienced. These included a (1) large open ward with approximately 25 dialysis stations, (2) a ward which had smaller rooms having four stations in each, (3) the small training room which typically has one or two stations and (4) the isolation room which only had one station. The large open ward (1) produced uncomfortable feelings of watching, seeing sickness and being watched. While training room (3) was experienced as set up to be intruded on by various hospital staff not involved with the participant. The room with four stations (3) allowed for a sense of bonding to develop amongst those in the room. However, the worst was (4) the isolation room which evoked a sense of horror reminiscent of punishment.

> ". . . when I was in the other room on the other side and when I was in isolation where you're just put into one room by yourself and you had your treatment going on that was horrible. Because you're sitting in a chair or lying on a bed for four hours, you just basically have to wait your time . . . and that's when the time really slows down."

Hospital or Home? Transformations and Negotiations of Lived-Space

In this grouping it was witnessed how having dialysis at home transforms the home into a hospital. During the interview with one participant in his bedroom, the transformations of his lived-space were revealed. It was witnessed by me that the participant's clothes dresser had been transformed into a medical-supply-storage-cabinet, and that the foyer outside his room was now a medical-supply-storage-room. With having less room due to the equipment now in his bedroom, he had to renegotiate space with his sister by switching his furniture for her smaller furniture. My observation of a tape measure left lying on his dresser led to a discussion that showed how he had applied careful thought and calculations to the layout and organization of his bedroom. Organization, it seemed, was the central criteria in transforming his small bedroom into a hospital-work-space. This transformational process reached alarming levels, when he disclosed that the blood for his weekly blood tests were being stored in the kitchen fridge, thus transforming it from a home-food-fridge, into a clinical-hospital-fridge.

> "My mother will come up, take the blood tubing [vial], put it into a cup and put into the fridge until the next morning."

This practice raises some safety concerns, as he lived with his extended family, which included nieces and nephews who were toddlers and who may have had access to the fridge.

Bodies Without Homes: Access Barriers for the Homeless and Renters

Here fundamental problems with home dialysis were revealed. In the case of the person who shared a machine, "I do it at somebody else's home," it became clear that she shared the machine because her home could not accommodate the machine and all it required.

> "So you combine everything, there's a lot of room that is needed, more room than I have and the water system, the water purification system wouldn't be good in my apartment because it's an old house and I don't even drink the water. The water's not clear and clean like the water you're drinking there. It's kind of like old pipes. It looks kind of rusty. It's good enough to bathe in and wash your dishes and stuff but I wouldn't advise anyone to drink from it. I always buy bottled water. So knowing that I can't really see them if they did a water testing and a water pressure testing it just wouldn't be feasible in my apartment . . . and it's not my home."

Her home did not meet the space requirements. Also she was concerned about the water quality in the place where she lived. In short, if one does not have a home, then one cannot have home dialysis. It is not just the homeless who cannot receive dialysis. Indeed renters, people who live in shelters and others who pursue the various other forms of shelter also will experience severe obstacles to receiving home dialysis. Thus "home" is more a criterion for service than just an explanation or description. In this way home dialysis is a barrier to service. When extended to home care in general, this also raises issues about universal accessibility.

Lived-Relations with Self and Others

Struggles Between the Body and Machine

In this cluster of themes the idea emerges that the participants (carbon) are struggling with the dialysis machine (silicon) itself. Participants seemed to struggle with how to relate to the machine. They produced complex ways to acknowledge its life saving qualities, while still maintaining control over it, and therefore their lives. Keeping the machine in its role as a machine was done by referring to it as being something that they were "hooked-up to." One participant acknowledged the seemingly opposing aspect of it as mundane and important, even divine, qualities of his relation to it to by saying, "It's just a machine. I don't worship it." However, sometimes the machine seemed to take on "it's own agenda." Hinting at the machine's human like qualities, a staff member said to one participant that it would become like his "girlfriend." The participant rejected this suggestion of personification by saying that it was just "a piece of technology."

Another participant talked about how the machine in his home was like a family member who needed to be taken care of.

> ". . . it becomes like I would say more or less like a family member.
>
> I've got to look after it.
>
> So I think it's just more it's like if you have children, it's your kids you have to, you'd do anything for it type of thing.
>
> . . . after a while you know how some married couples you'll have a person that snores . . . the other partner will get used to it, it doesn't even bother him anymore . . ."

A unique situation was revealed when one participant explained that she shared the machine with another HHDT dialysis patient, who was not in the study, but was her friend. Talking about the sharing of machine illuminated the strains placed on their relationship by this arrangement: "it gets kind of sticky when it comes to sharing the machine."

In a different situation, the machine was also used as way to mediate deficiencies in the hospital environment. When one of the participants felt too cold, and his concerns were not addressed by the staff, he would use the machine to raise his blood temperature.

> "I can change my blood temperature so the machine returns my blood at a warmer temperature, whatever temperature I set. And I would usually raise it to 37 because they had a climate control problem with this place and I was always cold. I get kind of cold easily. And one of the nurses would get really fussed about my doing this without asking."

This reveals subversive possibilities for the meaning and operation of the machine. In this way the machine became a site of resistance for his body, a place where potential was turned into action. He was using the machine in a new way, a way that it was not designed for. He had subverted its purpose and used it to overcome his environment to restore his body temperature: comfort. In this way the machine can be subverted from original and primary purpose and become an extension of bodily-resistance.

Lived-Body

Pleasure and Pain: The Last Frontier of Bodily-Resistance

This grouping of themes gave rise to the idea that lived-body, and its sensations of pleasure and pain were the actual points where aspects of the hospital's overwhelming institutional tendencies were held at bay. In one example a participant talked about how he resisted procedures for taking a bath, suggesting that the procedures introduce an unwanted institutional experience into the seemingly pleasurable aspect of bathing.

> "See I wouldn't want, I wouldn't want a recommended procedure for taking a bath and a recommended procedure for doing this. See that starts to compromise my day-to-day function. That's reminding me that I'm sick. I don't want to be reminded that I'm sick. I don't want to live around an institution."

One participant used medical-technical descriptions of inserting needles into his arm until he recalled the pain associated with the insertion. When this occurred he dropped the medical-technical descriptions of "veins" and "access site," and instead talked about how the needle "ripped the shit" out of his arm.

> "but when you're starting dialysis and cranking up your pump speed you're watching these to see if you might have a blow
>
> . . . I was always nervous at the Center that I would, because I didn't like cannulating there, that I would use too much force and I would poke through the other side of my vein . . . or just rip the shit out of it."

In this way the lived-bodily-experience of pain resisted the medical functional narrative. Laughter by nurses was also talked about as a way that helped to "de-institutionalize" the dialysis experience. Another participant, speaking to the dietary restrictions replaces the experiential notion of eating with the medical-functional terminology of "intake."

> ". . . so I really have to watch a lot of the things I intake . . ."

The life-world is thereby being assailed by medical-technical terminology/discourse. It would seem that the senses in and of, themselves are resistant to this terminology. Pleasure and pain, it appears, are sites for resistance against medical institutional discourse. Thus it is seems that everyday pleasures such as laughing, bathing, eating and even pain, are aspects of the life-world of these participants, which resisted the institutional tendencies of the hospital.

Function and Privacy: Embodied Wellness and the Struggles of Gendered Health

In this cluster of themes it became clear that gender difference existed between two of the participants in the way health was embodied and experienced. A male participant talked about how that to regain his health was to return to a body which functioned.

> "I'm trying to see if I can function as normal and I've been doing very good at it at being able to function as if I had no, no illness because it can be done. It's just that I'm just tailoring my dialysis prescription to incorporate that into my lifestyle."

He was struggling to see if he could "function as if" he was not "really sick." Thus he struggled between being a functioning body and a sick body. For the female participant, however, a healthy body was one which did not look unhealthy.

> "So people knew something was wrong looking at me, wow she looked healthy before, now she's so skinny."

When she was sick, her clothes did not fit her. This in turn caused her to perceive that people were looking at her as a person who was sick, which seemed to publicize her illness. Her desire was to have her body return to a weight which would not cause people to speculate about her health status.

> "No some people came and asked me what's wrong or what happened, why you know or some people reacted thinking I did something. Well a lot of people reacted saying wow you've lost a lot of weight. But I know deep in their mind that they were thinking how come she lost so much weight so soon? What's wrong with her you know? Of course people are going to think AIDS or cancer, all the big ones."

In this way her sense of health was related to her relations with others, while his was connected to his ability to function, suggesting that embodied health may have gender differences.

Transformations: Embodying Discourse and Practice

What emerged was how medical discourse and practice transformed the bodily-experience of the participants. Bodily-feelings of urination, and having a full bladder seemed to be relocated into the chest area, with a focus on poor breathing and a new sensation of being "overloaded." Additionally, urine was now experienced as a "toxin," which built up, and thus needs to be "taken-off."

Again, bodily-feelings and sensations seemed to have been overpowered by medical-functional discourse and practice, to the point where a graft was left in one of the participants arm, even though he wanted it removed. It was never taken out. He said that now he noticed it "only by feel," suggesting that it's function was fine: function over sensations. This participant, using medical-functional discourse, also referred to his chest as an "exit site." When doing so, he lifted his shirt to show me the "site." In effect demonstrating the now public nature his site/body. Another participant also talked about his body as a site. He talked about "handling his sites" which were located in his arm. In this way the body/site is becoming a site for medical intervention thus calling into question the sovereignty of their bodies. Perhaps the body needs to be objectified with a new terminology in order for procedures to be applied to it. If this is so, then "site" would be the suitable renaming.

Perhaps the most significant evidence of lived-bodily-transformation was best revealed when one participant described the incredibly difficult experience of having a graft left in his arm.

> R: ". . . so now I've got, I've got this graft in my arm that they don't want to remove right because it's not working. So now I've basically become a medical junkyard. My body, this part of my body has become a medical junkyard."
>
> I: "Okay so it's still in there."
>
> R: So they did something for me, it didn't work but now they don't want to take it out for whatever reason. Maybe there's a health complication that maybe it's more dangerous to take out or what have you. And I wasn't even informed of that. Well that's, when they said well they'd rather not take it out, I'm thinking well they don't want to take it out because I can function with it in my arm and not have it compromise my you know my health or my function ability or my motor skills. Or it basically costs you know to have the surgeon go in there, staff the operating room, book an operating room, all the costs associated with that. I'm sure they didn't want to put that money into it because you know I can function fine with it in there. I don't think, maybe that's what's my thing. There could be another reason where it might be, it might be a problem to take it out and there may be more health risks involved with taking it out than just leaving it there."
>
> I: "You don't have that information?"
>
> R: "That was the excuse they've given me but I, you know what I, I'm not a big fan of that explanation. I don't necessarily believe that, no."
>
> I: "You're not satisfied?"
>
> R: "No."

Here he worries about the cost of the medical procedures. In doing so it appears as though the institutional discourse of health care finances is having a direct impact on the patient's lived-bodily-experience, which in turn leads to a skepticism surrounding the reasons offered for a "medical" decision. It seems as if the institutional discourses of function, and finance, have overridden his personal sense of his bodily-integrity. The result is a cost-effective-functional-altered-body, which he experiences as a "medical junkyard." In essence, the institutional-hospital discourse has left its signature on/in his body. The result is having the status of his body downgraded from the status of a living-whole-body to a cost-effective-functional-altered-body, which in his experience is a medical-junkyard-body.

The lived-body is transformed by discourse and practice. Material bodily-integrity is be challenged by having "junk" left in it, due to function taking precedence over sensation and experiences. Additionally, sensations can travel from one part of the body to another, while natural body fluids such as urine are transformed into experiential toxins which must be removed. Moreover, certain technical terms such as "site" were found to attach to the body, thereby destabilizing its sovereignty by exposing it to the forces of medical development and thus revealing a struggle for sovereignty at a corporeal level.

LIMITATIONS

The limitations of this study must be understood from within the context of qualitative research and in particular phenomenology, as qualitative studies cannot be generalized in the same way as quantitative studies. As such, the goals of phenomenology are to describe and interpret the phenomena of the life-world. The way to increase the understanding of the participant's life-world would have been to increase the time spent with them. While a two-hour interview is in-depth, more time could have been spent with them. Additionally, a wider inclusion of data, such as participant observation of routine activities, and also photographs, poems, art-work, and journals from the participants could have been considered. Moreover, additional people could have been interviewed such as friends, family members, and even other members of the health care team. Thus the small "n" suggests caution in interpretation of the findings, especially with regard to the generalization of the results. Finally, I have not attempted to produce the definitive picture of the home haemodialysis technology experience. Instead, this study has produced a snapshot or description, and finally my interpretation, of four people at a certain time in a certain context.

DISCUSSION

The findings suggest clearly that the life-world of participants were transformed by HHDT and that the transformative nature of HHDT is far-reaching. The embodiment of these transformations was experienced in all the basic phenomenological themes—transforming the body, the home, relationships with self and others. It was evident from the findings that the discourse and practices of the hospital-medical-functional-world impacted all aspects of the participants life-world. These transformations have raised questions surrounding sovereignty of the body and bodily-integrity. Who owns the body after it has been transformed medically? Is bodily-integrity preserved experientially?

The data revealed that the experience HHDT cannot be separated from the other areas of the participants lives. That is when the participants were asked to speak about their experiences with HHDT, they also chose to talk about other experience they have had with differing modalities of dialysis. In this way HHDT can be seen as experientially related to other dialysis experiences. This is helpful and may suggest the necessity for future researchers to consider differing modalities of dialysis as related and not separate.

The findings did not support those of Nagle's (1995) study, where it was reported that the embodied self was preserved in the face of technology. However, Nagle did not locate embodiment within the context of lived space, lived-relations with other and self, and lived-body. Additionally, Nagle focussed on the experience of individuals receiving in-hospital dialysis, and not home dialysis. This may explain the difference in findings.

Of particular interest is the finding that the transformative quality of the hospital-medical-functional-discourse, and practice, simultaneously impacted the body and the home. This was revealed in the reconstitution of the hospital in both the home and the participants' bodies. Beyond embodied transformation as already discussed, this raised the question of the use of the term home in home haemodialysis. Those who rent, sublet, or pursue other forms of shelter, may not have a home to be transformed by the hospital, while those who are homeless do not. Thus they will not receive the benefits of home haemodialysis. Home haemodialysis effectively sets up some barriers to people who rent, and a permanent barrier to those who experience homelessness. This is disturbing as people who are homeless already face considerable barriers to health care (Jahiel, 1992).

Additionally, the transformation of the home into a hospital was revealed. Wellard and Street (1999) describe a similar finding in their study on home haemodialysis whereby each family they studied eventually established a clinic in their home, thus supporting this study's findings. However, Wellard and Street did not discuss the implication of this factor on home and workplace safety. Moreover, examples of unsafe working/living conditions were found, such as storing blood in the kitchen fridge. This highlights the necessity for further investigation in the area of developing health and safety protocols for dialysis within the home environment.

An interesting challenge is posed to Toombs' (1988) suggestion that the lived-experience of illness is more about a disruption of the life-world, than it is about the disruption of the biological body. Findings in this study suggest that the lived-experience of illness is impacted by the medical-functional-discourse and practices of homehaemodialysis technology. This impact thereby prompts the embodiment of the discourse and practice framework, allowing for an experiential transformation of the lived-body as well as the life-world with which it is intertwined. This creates conceptual space for the consideration that the life-world is not excluded from the discourse of the biological body. With this opening one can see how the life-world is transformed, and finally embodies technological discourse and practice.

RECOMMENDATIONS RESEARCH AND PRACTICE

Phenomenological based research design is a growing area of research. Its methodological significance in exploring the lived-experiences of people who receive

HHDT has proven valuable in enriching our understanding of the life-world of these individuals. Continued research in this area is necessary to expand our existing knowledge of the implications of this form of technological treatment on the individuals and families who experience it and those who provide it. Of benefit would be research focused on exploring the implications of other forms of technological medical treatment on the life-world of the recipients to further illuminate our understanding of the process of embodied transformations across medical treatments. Future initiatives could include a longitudinal phenomenological study focused on exploring the lived-experience of people receiving home haemodialysis over time. This research would aid in providing a deeper understanding of the process and long-term implications of embodied transformations. Future research might also include a multi-method study such as an Ethnosurvey (Singleton & Straits, 1999) to allow for the generalizability of results. Once a substantial inventory of research is available across dialysis treatment settings (in-hospital and in-home dialysis), comparative research could be conducted. Given that in an exploratory study such as this, it is initially useful to start with a homogenous sample in social terms to explore the range and meanings with a similar population, the second phase of research however, might incorporate issues of diversity.

Implications for social work practice would include ensuring that the same consideration to health and safety standards within the hospital be applied within the home setting. Given that this study highlighted instances of unsafe practices, there is a need to develop a mechanism that monitors health and safety protocols within the home. In light of this finding, a review of the health and safety standards for home haemodialysis may be called for.

Isolation rooms need to be reviewed in terms of social isolation. For some people, social isolation may be the most serious social punishment available. Patients in isolation rooms need special attention to be protected from possible severe negative consequences, which occur alongside of medical isolation. Hospital room configuration could be matched to the patient's social comfort needs. For example, some people may prefer to be in small groupings, while others may benefit from larger groupings. Ideally, a variety of possibilities would exist.

Medical technical-discourse and practice procedures need to be administered in ways that support the integrity and sovereignty of the lived-body. Ways of doing this may be approached by employing plain language when educating and treating patients. Given the complicated relationship that exists between the patient family and machine, and the relative ease with which the dialysis machine is incorporated into the family unit, routine social assessments should consider the patient and family's experience of the dialysis machine.

The implications of this study go beyond developing practices and policies specific to HHDT. In the wake of both federal and provincial government funding cutbacks to subsidized housing, the development of housing initiatives has halted. At the same time, medical treatment and care within the home is increasing. For one to experience HHDT, a home is integral to treatment. Therefore there is a need for social workers, as well as the multi-disciplinary teams they work with, to advocate for increased funding for social housing initiatives that enable patients who are most in need to access subsidized housing.

Social workers with this new information should be able to develop sensitive and caring multi-level interventions for people who receive HHDT. Thus, it is hoped that this study highlights the need for this population to be seen outside the admittedly overwhelming medical framework of 'stimulus and response' so prevalent within hospital based social work.

Phenomenological research is beneficial to the field of social work as it helps to illuminate the complexity of the human condition. In particular, in an increasingly globalized world that generates multifaceted and subtle environmental, societal and personal transformations, a sensitive framework, like phenomenology, is well situated to detect the nuances in our ever-changing life-world. Other frameworks may be helpful once nuances have been understood phenomenologically. Phenomenology, however, will aid in the detection of changes as experienced in the life-world of people in ways other frameworks cannot. In this way, phenomenology, embodiment, and by extension-the lived-body, can be said to be the final resting places of all social developments. As such, a shift to seeing the lived-body and the life-world it dwells in, as a valid starting point for social work research has been highlighted by this study.

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Evaluation Research on the Effectiveness of Social Work Intervention on Dialysis Patients: The First Three Months

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The research reported in this article examined the effectiveness of a dedicated, timed and recurring Master's level social work intervention with patients new to dialysis. Study participants were evaluated for depression and levels of adjustment when first beginning dialysis and three months later. A control group received standard, mandated social work services while the experimental group received an additional counseling component. The experimental group showed statistically significant changes over time in lowered levels of depression and maladjustment.

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INTRODUCTION

In 1996, approximately 214,000 Americans received dialysis treatment for end-stage renal disease (ESRD Facility Service, 1996). Beginning in 1976, federal regulations have required social work participation in all dialysis units. Since the inception of these services, professional social workers (trained at the Master's level) have developed a variety of program interventions to address the myriad of psychosocial needs of the dialysis patient.

In this economy of managed health care and cost-benefit, social workers are particularly compelled to evaluate their professional activities as allocations for funding are more rigorously reviewed. The evaluation of social work activity on behalf of the dialysis patient is timely and warranted both for the profession, to advance knowledge on behalf of the consumers we serve, and to stand the test of scrutiny in times of budget analysis and downsizing.

Using an experimental design, the research described in this article examined the effectiveness of a dedicated, timed, recurring social work intervention with newly admitted dialysis patients to the dialysis center of a local mid-sized suburban hospital. The major hypothesis of the study was that there would be a statistically significant change in levels of depression and adjustment for those patients receiving the weekly M.S.W. psychosocial intervention. A goal of the study was to be able to provide existing dialysis programs with a statistically supported model of service.

THE DIALYSIS EXPERIENCE

Dialysis as a life-saving treatment was introduced in 1960 by Dr. Belding H. Scribner, the developer of the dialysis machine. Patients with kidney failure cannot cleanse their bodies of the wastes normally flushed by the kidneys in urine. Dialysis is a way to cleanse those toxins and wastes that build up in the blood which normally would be excreted through urination. During dialysis treatment, a patient's blood is carried from the arm through plastic tubing to an artificial plastic kidney (dialyzer) which removes wastes (salt and urea) from the blood. The blood is returned to the body through a second tube. In the United States, dialysis usually is performed three times a week for a minium of three hours each session. Without the treatment or a kidney transplant, the patient with end-stage renal disease will die within weeks.

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Dialysis machines do not replace nor are they as efficient as normal kidneys. As such, while they sustain life, serious changes in life style and personal independence occur. The dialysis machine enables the patient to make up for some bodily functions but serves as proof of thepatient's inability to control some of their bodily functions and have a sense of control over their lives (Ilic, Djordjevic, & Stefanovic, 1997).

Dialysis patients require special dietary care and medications; there is change in body image and function including the loss of urination and physical energy, loss or change in sexual function, changed appearance due to surgery and other signs of physical deterioration, are typical (Berkow, 1987). Many dialysis patients are unable to work because of their illness and the demands of the scheduled treatments (Frazier, 1981).

The emotional strain of dialysis is manifested in many patients with ". . . deteriorating levels of self-esteem, a gross reduction in social, recreational and sexual activity with associated loss of interest and involvement, and disappointing levels of vocational rehabilitation {often reported below 50 percent}" (Nichols & Springford, 1984, p. 563).

Psychosocial stresses are a fixed feature of the lives of dialysis patients. The psychosocial literature on the effects of dialysis are generally divided into two major areas: studies on the prevalence and impact of depression on the patient and studies on patient adjustment described as quality of life issues.

Depression

As the quality of dialysis treatment has improved since its inception in 1960, psychological factors have become an important aspect of treatment and are often used as a predictor of the patient's ability to cope with the rigors of treatment. The study of depression in dialysis patients has become a concern for health care providers because of the role that depression plays in patient compliance and their ability to return to their pre-illness level of activity and functional status.

A review of the literature reveals that the incidence and prevalence of depression among dialysis patients is estimated to vary from 20 to 100 percent. Beginning in the 1970s, the literature on depression and dialysis began to document the incidence of depression in dialysis patients. Early studies tended to report a high incidence of depression with psychiatric complications as the norm. The generalizability of these studies may be debatable as sample size was usually small. A sampling of the literature shows a study by Shea, Bogdan, Freeman and Schreiner (1965) who noted degrees of depression in 6 of 9 patients. Reischman and Levy (1972) reported 100% depression in all 25 of their patients beginning dialysis; and Kaplan de Nour and Czaczkes (1976) found a 50% incidence in 89 dialysis patients.

More recent studies, often using larger sample sizes, standardized test materials and more comparative reporting between medical staff and patient perception, continue to document this relationship. A sampling of these studies include: Smith, Hong and Robson (1985) 78% of 60 patients were depressed; Hinrichsen, Lieberman, Polack and Steinberg (1989) 24.2% of 124 patients; Sacks, Peterson, and Kimmel (1990) 60% of 57 patients; Kimmel, Peterson, Weihs, Simmens, Boyle, Verme, Umana, Veis, Alleyne and Cruz (1995) 100% of 149 patients with symptoms of depression. This data continues to support the prevalence of depression in dialysis patients.

Several of the above mentioned studies used the Beck Depression Inventory (Beck, Ward, Mendelsohn, Mock & Erbaugh, 1961) as one of the methods of assessing depression (Kimmel et al., 1995; Sacks et al., 1990; Smith et al., 1985) in their patient cohorts.

Adjustment

Health related quality of life is an inclusive term which emphasizes physical, social, and psychological variables inherent in adjustment to illness (Mozes, Shabtai, & Zucker, 1996). Satisfaction with quality of life in dialysis patients is related to adjustment (Morris & Jones, 1989); adjustment is related to compliance and the ability of the patient to return to their pre-illness functional status.

Adjustment to dialysis is frequently described in relation to how the patient adapts to the multitude of stressors posed by the routine and restrictions of treatment. Several studies have documented the challenges faced by dialysis patients and, depending upon which study, have rank ordered the stressors according to severity. They include: weakness, having to reduce work, fluctuating health, dependence on others (Matthews, 1980); fluid limitation (Baldree, Murphy, & Powers, 1982); loss of energy, insomnia, decreased sexual interest (Craven, Rodin & Johnson, 1987); fatigue and boredom

(Bihl, Ferrans & Powers, 1988); muscle cramps and disruption of work (Fuchs & Schreiber, 1988). Several of the studies used the Psychosocial Adjustment to Illness Scale as one of the measures of adjustment.

For the patient on dialysis, it is estimated that one third to one half do not comply with either dietary or fluid restrictions and/or do not spend the requisite amount of time each week on the dialysis machine (Rocco & Burkhart, 1993). Either of these situations can have a profound impact on the well-being of the patient and can result in deterioration of the individual, hospitalization and protracted health problems.

Adjustment and depression are important concerns in health care for dialysis patients as they relate to functionality on the micro level and allocation of health care resources on the macro level (Ferrans & Powers, 1993). For this reason, these variables—adjustment and depression—were chosen as the measurable dependent variables of this study.

The First Three Months

As with most diagnoses of chronic illness, the patient is prone to feelings of profound emotional upheaval upon receiving the news of their condition and the need for ongoing dialysis treatment. Even though most dialysis patients have known of the deteriorating condition of their kidneys, the impact of being informed that they will require dialysis is shocking. Indeed, Gorman and Anderson (1982), MSW social workers in a dialysis unit, observe that ''The immediate reaction of the patient to the diagnosis of chronic renal disease (necessitating dialysis) is that of incomprehension. It is impossible for the person concerned to take in the full meaning of the diagnosis at its first telling'' (p. 39).

For the patient who is beginning dialysis, several assumptions about their physical and emotional condition can be made. The individual is sickly, usually ailing for a protracted period of time; the individual is frightened, distressed and unsure. Depression is common, quality of life is deteriorated or in flux.

The emotional well-being of the patient is severely stressed. Dialysis patients go through a grief process which begins with the initial loss of kidney function, often accompanied by a loss of overall mental and physical functioning.

The challenges of the early months are strenuous. The adaptation to the routine of dialysis treatment is experienced by most patients as disruptive and sorting out the details of work, transportation, finances and the impact on the caregivers are enormous tasks for an ailing individual. Attention to diet, fluid intake, and medication pose further difficulties. Often patients experience profound changes in motivation resulting from fluctuating uraemia (accumulation of toxins in the blood due to the failure of kidney function) which causes a reduction in energy and strength. At least half of those patients, new to dialysis, experience some physical difficulties compounded with problems of skin irritation, headaches, nausea, and sleep disruption (Nichols & Springfield, 1984). Sexual dysfunction is reported in a high percentage of patients (Levy, 1984). In summary, it can be asserted that the first weeks on hemodialysis are a time of major physical and psychological strain.

Because of the unique stresses in the first three months, this period of time was selected for evaluation of the social work intervention.

STUDY METHODS

Research Design

The type of design chosen for this study was an experimental design. It employed a nonequivalent control group since a perfectly matched control group was impossible. In this type of study, two groups with similar characteristics are compared before and after the introduction of the treatment variable (Frankfort-Nachmias & Nachmias, 1992).

Random assignment to each group—the process whereby cases are assigned to experimental and control groups—ensured that each case had the same probability of being assigned to either group. This method of assignment strengthens the external validity (the extent to which the research findings can be generalized to larger populations and applied to different settings) of the research study.

Instruments

Two assessment instruments were used for this study: the Beck Depression Inventory (Beck, et al., 1961) and the Psychosocial Adjustment to Illness Survey (Derogatis & Derogatis, 1990).

The Beck Depression Inventory (BDI) was used to assess the level of depression of each patient entering the study. The BDI is a 22-item questionnaire that requires the respondent to indicate the relative presence of emotional, behavioral, and physical symptoms associated with depression during the week prior to the assessment (Smith et al., 1985). The BDI is a well-validated index of depression and correlates well with diagnostic criteria. The advantage of the BDI is that it places the participant within a range of depression (Sacks et al., 1990). A BDI score of greater than 15 has a high sensitivity, high specificity, and predictive value for diagnosing depression (Kimmel et al., 1995).

The Psychosocial Adjustment to Illness Scale (PAIS) has been used in medical research and has established norms for psychosocial adjustment. It reflects adjustment via seven domains: health care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress. A total of 46 questions are asked of the subject. According to the developers of the instrument, ‘‘ . . . The PAIS is appropriate for the assessment of any medical condition that has an identifiable psychosocial component’’ (Derogatis & Derogatis, 1990, p. 7). A score of 60 or over indicates clinical levels of psychosocial maladjustment. As the PAIS has been used in several studies with renal patients, normative scores have been established for this cohort. Internal consistency within the renal cohort domains ranges from .63 to .81 (Derogatis & Fleming, 1996). Reliability for the PAIS has been determined based on several patient populations with correlations ranging from .56 to .86. Validity was assessed by utilization of the PAIS in several studies with ratings of .60 to .81 (Derogatis & Derogatis, 1990).

While there is some repetition in content between and among the two instruments, the interplay between them was expected to yield a composite of the dialysis patient covering all aspects of adjustment.

Beyond the two instruments, demographics and background data were also collected on each patient including the participant’s age, gender, marital status, living arrangements, race, religion, occupation, education level, and income.

Procedure

The majority of participants were recruited from the inpatient hospital population where they went through an initial orientation to the dialysis unit. This orientation is done in the hospital by M.S.W. social workers dedicated to the dialysis unit. While some dialysis is performed in the hospital, ongoing treatment is done at the free-standing dialysis unit.

The researcher was contacted when a new patient was admitted into the unit, met with the new patient and introduced the study noting that participation was voluntary. Informed consent was obtained. Patients were told that this was a study to determine the effectiveness of social work intervention. Patients were not told whether they were in the experimental or control group. The issue of confidentiality was assured as each patient participating in the study was assigned a number by the researcher. All records pertaining to the study were kept off-site in the office of the researcher. Patients were reassured that compliance in the study would in no way impact their medical or social work experience in the unit and that they were free to withdraw from the study at any time.

Upon gaining consent to participate, patients were administered the Beck Depression Inventory and the Psychosocial Adjustment to Illness Scale by the researcher. Demographic information and administration of both tests was done while the patient was undergoing dialysis to minimize possibly confounding influences due to the accumulation of uremic blood between treatments (Devins, Binik, Hollomby & Barre, 1981). Staff social workers—5 MSWs—were informed of the status of the new patient the following day and social worker services were initiated.

It is important to note that all patients, by federal mandate, receive social work services upon entrance into the dialysis unit and receive services for as long as they are dialyzed there. The control group therefore, was not deprived of social work services; the experimental group received additional service on a scheduled, weekly basis. Patients in both samples were reinterviewed at three months with the same battery of tests being administered. Research was completed at the end of thirteen months.

Social Work Intervention

Since 1976, the federal government has mandated social work services in dialysis units. In response to the mandate, the National Kidney Foundation (1991) and the National Association of Social Workers (1994) have developed guidelines for Master’s level nephrology social workers. Essentially the guidelines for services respond to the multiple needs for assessment, resource procurement, team planning, advocacy, referral and education and the ability to monitor interventions. According to the guidelines, clinical intervention (counseling) must be available if the family or caregivers request the service.

Social workers are positioned in a unique place in a patient's life; they are trained to view the patient in their multiple social systems and function from a person-in-environment perspective. Because social workers do not provide direct medical treatment, they are often the team member best suited to provide consistent ongoing contact with the patient when the patient and family are struggling to come to grips with their initial diagnosis and engage with the routine and rigors of dialysis (Gorman & Anderson, 1982).

Due to the high caseload levels in most dialysis units, intensive clinical casework with patients is difficult to arrange and is only possible under near-crisis situations. One study noted that nephrology social workers were able to allocate less than one-third of their time to patient counseling (James-Rogers, Widrown Schwankovsky & Ragson, 1992). Many dialysis patients feel that the only reason that they are having psychological problems is because of their illness and they resist engaging in problem-solving counseling unless there is a psychosocial crisis (Frazier, 1981).

The structure of the social work intervention was framed by the need to help the patient make the initial adjustment to treatment. It had a psychoeducational component, a supportive component and a clinical component. The psychoeducational component included providing available information on the concrete needs of the patient undergoing dialysis. This is part of the basic social work assignment, as per federal regulation. This component was similar in both groups. The social support component is also the norm as per regulation but for those receiving the intervention, additional levels of inquiry and effort were implemented on a sustained basis. The beneficial role of social support in illness is well established and has formed the theoretical orientation of many group and individual interventions practiced by social workers. In offering additional social support as part of the intervention, the social worker was helping the patient mobilize themselves as well as assessing and accessing additional supports as needed. The clinical component had the social worker exploring the patient's subjective reactions and responses to beginning dialysis, normalizing their reactions when appropriate, while stressing the aspect of hopefulness. This aspect of the social work services is not mandated and required the social worker to continue to follow stated concerns of the patient, explore their fears and essentially establish a counseling relationship. Traditional social work principles of casework intervention were utilized, including the need for empathy, focused listening and exploration. While not following an exact script, it was intended that the 20-minute additional weekly social worker intervention would go beyond the concrete needs for arranging transportation, for example, and be more focused on the impact of beginning dialysis on the individual and significant others and on the emotional and support needs of the patient.

At any given time each social worker carried both experimental and control cases, based on staff shift allocation and availability of dialysis machines for new incoming patients. Five social workers formed the staff of the dialysis unit. All of the workers were experienced renal social workers having had an average of 6-12 years of practice on a renal unit. Staff were involved in the conception and design of the intervention. This helped in terms of staff commitment to the project and conformity to the intervention protocol. During the tenure of the study, one staff member resigned from the unit and a new worker, also experienced, replaced her. The new worker was informed of the study and picked up both the intervention and control cases held by the former worker. During the study period, the researcher met with staff both informally (while interviewing) and formally to monitor progress and determine adherence to the intervention design.

FINDINGS

Participants

A total of 55 participants were initially interviewed in the study. Before reaching their three-month reinterview date, four participants died, one began dialysis at home and four were hospitalized too long to remain in the study (over one week). The final sample consisted of 46 participants; 23 participants were in the experimental group and 23 formed the control group. Independent sample t-tests of the two groups—the intervention and control—revealed that there were no significant differences between the groups on the demographic variables. Table 1 shows the characteristics of the study group.

It was important to establish the similarity of the two groups to see whether there might be an external (demographic) factor which would explain the findings rather than the independent variable (the intervention). If for example, one group had a significantly higher income level, it might become an explanation for the levels of depression or adjustment within the group. This was not the case.

TABLE 1. Characteristics of Study Participants

	Treatment (n = 23)	Control (n = 23)	Chi-Square
Gender (%)			NS*
Male	14	15	
Female	9	8	
Ethnic Group			NS
White	20	16	
Non-white	3	7	
Educational Level			NS
High school	13	10	
High school +	10	3	
Marital Status			NS
Married	13	15	
Not married	10	8	
Living Arrangements			NS
Live with someone	18	20	
Live alone	5	3	
Mean age	60.7	63.3	NS
Income (total household)	$37.991	$39,891	

*NS = Not Significant
$p > 0.000$

In viewing the experimental and control group as an entity, before the initiation of any intervention, scores on the BDI indicate that 76% of the cohort (n = 46) registered mild to moderate levels of depression and 24% were moderately to severely depressed. This figure is slightly higher than the average of studies cited in the literature review which used the BDI as their reference point. After three months, with the initiation of the intervention and/or the baseline social work services, the entire participant group showed a lowering of depression with 97% registering mild to moderate depression, and 3% moderately to severely depressed.

Similarly, in terms of adjustment, the cohort (n = 46) measured a 70% level of maladjustment at the beginning of their dialysis and a 13% level of maladjustment after three months.

That both groups—the control and the intervention group—showed improvement over time is supported by findings that as patients experience relief from, or are better able to tolerate the physical disturbance associated with dialysis, their depression and adjustment difficulties are lessened (Kutner, Fair, & Kutner, 1985).

Social Worker Effectiveness

The primary measure of impact of the MSW intervention was in comparing the differences of the mean scores on the Beck Depression Inventory and Psychosocial Adjustment to Illness Scale for each participant over the three month period of the study.

In viewing these scores, it must be noted that the guidelines for the Beck Depression Inventory indicate that participants with scores ranging from 0-9 fall within the normal range for depression, 10-15 experience mild depression, 16-19 mild to moderate depression and 20 and up moderate to severe depression. While both groups showed improvement, the control group still scored mild to moderate levels of depression after three months while the intervention group was scoring toward the lower end of mild depression. On the Psychosocial Adjustment to Illness Scale, guidelines indicate that scores of 60 and above show clinical levels of psychosocial maladjustment. The nonintervention group was still registering levels of maladjustment after the three month period while the intervention group showed greatly improved levels of adjustment.

To evaluate whether the changes over time were significant, the differences between test time one and test time two (three months later) were calculated for both the BDI and the PAIS. On the Beck scale, the intervention group showed a reduction of 6.4 compared to a 2.4 reduction for the control group. The two sample t-tests of these differences shows a mean difference of 4.0 which is highly significant (p > .000). On the PAIS, the intervention group showed a reduction of 17.5 compared to a 3.7 reduction for the control group. The two sample t-tests of these differences shows a mean difference of 13.7 which is highly significant (p > .000). Table 2 shows these findings. While each group showed changes over time, the intervention group had a highly significant reduction in both the level of depression and degree of adjustment.

LIMITATIONS

Several limitations of the study must be noted. The sample size was small which limits the statistical power of the design to detect and rate effects. In spite of the small sample size, no significant sociodemographic differences were found between the experimental and control groups.

While the sample was randomly selected, it must be noted that the participants are ill and often may be struggling with several physical complications while

TABLE 2. Difference in Changes Over Time (Three Months)/Group Statistics and Independent Samples

Group Statistics

	Pts	N	Mean	Std Dev	Std Error Mean
Difference in Beck Scale	Intervention	23	6.3919	2.407	2.5019
	Control	23	2.4348	2.272	9.4739
Difference in PAlS Scale	Intervention	23	17.4783	6.9535	1.4499
	Control	23	3.7826	2.984	1.6222

Independent Sample T-Tests

	t	df	Sig (2 tailed)	Mean Diff
Difference in Beck				
Equal variance assumed	5.731	44	.000	3.9565
Equal variance not assumed	5.731	43.856	.000	3.9565
Difference in PAlS				
Equal variance assumed	8.680	44	.000	13.6957
Equal variance not assumed	8.680	29.84	.000	13.6957

$p > .000$

adjusting to dialysis. As well, the study did not employ any pretest procedures to determine the psychological profile of the patients before dialysis treatment began. It was anticipated that random assignment to groups would address both of these possibilities and threats to internal validity.

This study is limited in its predictive ability as it looked at patients for only three months. Inferences for the future depression levels and adjustment for these patients can be made but they cannot be statistically supported without further research on this cohort.

The study results are to be seen as a pilot effort to evaluate or suggest a form of service. Further research demands a longitudinal study designed to test whether the initial findings have protracted impact on the dialysis experience of these patients and on those who care for them.

DISCUSSION

The outcome of this evaluation study suggests the effectiveness of an MSW intervention on the lives of first-time dialysis patients. The findings showed that there were statistically significant decreases in levels of depression and degree of psychosocial maladjustment in both groups over time, with the intervention group demonstrating a statistically significant degree of change in both these areas. These findings demonstrate that the social worker intervention which goes beyond the articulation of the federal mandate of service by including a more in-depth counseling component, impacts the initial dialysis experience.

The goal of social work intervention for the patient new to dialysis is to stabilize the individual and move him/her toward full rehabilitation. Those patients who are at greatest biopsychosocial risk due, in part to depression and poor adjustment, are prone to medical complications and disruptions in their levels of compliance (Kimmel et al., 1995). Depression in patients on dialysis has been found to be a predictor of mortality (Shulman et al., 1989; Burton, 1986) and places many patients at risk for suicide (Ilic et al., 1996; Hitchcock, 1992; Santiago & Chazen, 1989) by noncompliance. Early intervention has shown to have a positive effect on dialysis patients being able to maintain and/or return to work after the initiation of treatments (Raiz, 1996; Grumke & King, 1994; Rasgon, 1993). The findings of this study suggest that early social work intervention could be helpful in addressing many of these critical areas.

On a macro level, medical care in the United States is currently being defined in terms of resource management and cost effectiveness. Managed care has emerged as the strategy to address these areas (Cornelius, 1994). Under managed care, all levels of output toward the ill, both chronic and acute, are or have been scrutinized and, in most cases, have been ‘downsized.’ Social workers, along with many of their health care colleagues have had to ‘justify their existence’ as budgets have been attacked. In view of the findings, that early social work intervention positively impacts depression and adjustment, it can be assumed that the efforts of the social worker, refocused in the direction suggested in the study, would enhance the level of functionality of the patients. Functionality translates into less time in lost wages, fewer visits to the hospital or physician, lower medical costs and enhanced quality of life. As this is the goal of managed care, social work will have contributed in a more substantive way to its vast array of services.

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Struggles, Strengths and Strategies: The Lived Experience of Healthy Siblings of Children with End Stage Renal Disease

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The lives of persons with End Stage Renal Disease (ESRD) have been extended through the development of dialysis and kidney transplantation. However, along with this biotechnological and pharmacological advancement, relatively little attention has been directed to the impact of ESRD on other members of patients' families.

Drawing from a family systems perspective, stress imposed upon one member of a system is believed to also impact upon others within that system. In the case of childhood ESRD, the chronicity and prominence of the disease and treatment within the family, may increase the likelihood that others in the family are also affected. Until recently, siblings' experiences have been largely unrecognized,[1] *or determined from observation or parental accounts of the impact of illness on the family.*[2,3]

How healthy siblings of children with ESRD experience their lives is thus not yet well understood. Research questions addressed in this study include an examination of how these siblings view themselves and their daily lives within the context of their family. How do siblings organize themselves within a family routine of care for the child with ESRD? To what extent and how are siblings' developmental needs achieved? What are siblings' coping practices and strengths in managing their world?

LITERATURE REVIEW

Few studies examine the experiences of siblings of children with ESRD,[4,5,6] however a growing literature has emerged which addresses the experiences of healthy siblings of chronically ill children. This literature is largely inconsistent and inconclusive, and until recently, many studies failed to elicit the perceptions of the siblings directly, instead relying heavily on maternal accounts of siblings' experiences.[7]

Several studies portray healthy siblings of chronically ill children as overburdened.[8] Siblings are reported to provide caregiving activities for ill children,[9,10,11] and may engage in play activities less frequently than children who do not have an ill sibling.[12] Further, these siblings may be at risk emotionally, behaviourally, academically and psychologically.[13,14,15,16,17,18,19] In a random sample of over 3,000 Canadian children, siblings of children with chronic health problems were twice as likely as peers to experience emotional disorders.[20]

Several studies report sibling rivalry and jealousy toward the ill child,[21,22,23] social isolation,[24,25,26,27] and embarrassment about the sibling's condition/disability.[28,29,30] Also, school problems are widely reported among siblings of ill children.[31,32,33,34,35] Although healthy siblings may be at risk of developmental problems or distress, they may suppress their thoughts and worries in what Seligman (1987) terms a "web of silence."[36]

Contradictory evidence reports less negative impacts on healthy siblings.[37,38,39,40,41,42] Several studies posit that siblings of chronically ill children may be more kind, tolerant, helpful and/or empathetic than children unaffected by chronic illness.[43,44,45,46,47,48] Notwithstanding reports of higher levels of stress among families with chronic illness,[49] healthy siblings are noted to develop coping strategies which mediate the stresses.[50,51,52,53] Parental attitudes and/or available information are reported to impact upon siblings' adjustment to a chronic illness in the family,[54,55,56] however several studies also attribute sibling adjustment and coping to individual factors that are particular to the individual sibling.[57,58,59] For instance, several studies report cognitive and behavioural strategies used by siblings to mediate the impact of the illness, and optimize coping.[60,61] These include activities such as imagining life differently, talking to and spending time with others, becoming immersed in school projects or other activities, and changing behaviour patterns to accommodate other responsibilities in the household.[62]

While few early studies address relationships and interaction among siblings in families with childhood illness,[63,64,65] recent studies have increasingly examined the interactions of siblings and their chronically ill brother or sister.[66,67] This focus has not only illuminated the impact of ill children on their healthy siblings, but also addressed the contribution of healthy siblings in impacting upon the ill child, and mediating the effects of illness. As an example, Janus and Goldberg[68] examined sibling empathy toward children with chronic illness, concluding that increased sibling empathy is positively associated with prosocial behaviour toward the ill child. This study exemplifies a growing interest in the complex multi-dimensionality of lived experience and chronic illness, both for ill children and healthy siblings.

In summary, the literature addressing healthy siblings of children with ESRD is limited by an insufficient volume of research. A more broad review of the literature addressing siblings of children with various childhood chronic conditions illuminates conceptual and methodological flaws within existing studies. Conceptually, many of these studies generalize and avoid the distinctiveness of chronic illnesses or handicapping conditions, hence the unique impact of particular illnesses, such as ESRD, on siblings is left largely unrecognized.

Earlier literature tends to elicit psychopathology in siblings, yet ample evidence of contradictory evidence is also present. As noted by Leonard,[69] such inconsistencies in the literature may reflect not only a lack of sufficient evidence but also a depiction of the complexity and multi-dimensionality of siblings' daily lives of vulnerability and resilience.

Methodological flaws are also present in the literature. Anecdotal qualitative studies commonly lack reference to methods of establishing trustworthiness. Quantitative studies tend to use a cross-sectional design based on retrospective data. As yet, relatively few longitudinal studies address the experience of healthy siblings over time.[70] [71] Adjustment and adaptation, as an ongoing and integral part of human experience, is thus largely obscured by portrayals of siblings as victims without recourse or resilience.

Despite these shortcomings, the literature does give evidence of unique challenges encountered by siblings of children with chronic illness, as well as strengths and strategies in adjusting to, and/or surmounting their challenges. To the extent that the realities and complexities of siblings' lives can be understood, clinical interventions and health policy can be directed in ways which mitigate problems and foster strengths. In pursuit of this aim, a greater understanding of the realities of these healthy siblings of children with ESRD, is warranted. The central aim of this pilot exploratory study is to identify common characteristics and experiences of healthy siblings of children with ESRD.

METHODOLOGY

To determine healthy siblings' issues, characteristics, experiences and definitions, an ethnographic study was designed to allow exploration of siblings' perceptions. Thirty healthy siblings of children with ESRD were interviewed using open-ended, long interviews.[72] A purposive sample eliciting maximum variation was drawn from a listing of all children treated by dialysis or transplantation therapies at a large pediatric teaching hospital in central Canada. Trustworthiness of the findings was demonstrated through the following methods, outlined by Lincoln and Guba:[73] persistent observations, verification of data, negative case analysis, peer debriefing, member checking, reflexive journaling, and member checking.

RESULTS

Participants ranged in age from five to 18 years with a mean age of 15.2 years. Their ill siblings received varying ESRD treatments: peritoneal dialysis (n=10), hemodialysis (n=7), and renal transplantation (n=13). ESRD patients were generally stable, however six had recently experienced acute illness and hospitalization. Duration of illness varied from four months to 18 years with a mean of five years.

Participants all lived in the same home as the child with ESRD, except for two adolescents who had recently left the family home. Some 23 participants lived with both of their parents. The biological parents of five participants were divorced or separated, and except for one family, these children all lived with their biological mother, and in some cases, a step parent. In two participants' families, one parent had died leaving only one caregiving parent.

Twenty-four of the participants lived within commuting distance of extended family members including grandparents, aunts, and uncles. Of those whose extended family were not within commuting distances, their parents had, in four cases, immigrated from other countries in Africa, Asia and Central America. Five participants had not been born in Canada, and half of the sample was of a non-North American culture-of-origin.

In terms of the geographic location of participating siblings' homes, there was substantial variation. Almost one quarter of the siblings (n=7) lived in rural communities (population<10,000), with the rest (n=23) living in urban or suburban centres. Seventeen participants lived less than 60 miles from the treating hospital. Most of the siblings attended school (n=24). Of the six participants not in school, two adolescents had completed high school and of these, one was working and one was unemployed. Four participants had not yet completed high school, but were neither attending school nor employed.

When participants were informed of the study, several commented that it was “strange” or “unusual” that I would be interested in their perceptions. Several stated that the impact of ESRD on them as siblings was seldom considered or solicited. They viewed the daily care of the child with ESRD and their medical treatment and periodic hospitalization, as unremarkable, assumed and typical. Yet, despite viewing this as ‘typical,’ healthy siblings consistently confided about challenges, struggles and benefits that they faced—which, they believed, were associated with their sibling’s ESRD. Emergent themes, as outlined below, were: (1) increased tasks and roles; (2) feeling “left out;” (3) experiencing changes in peer relationships; and (4) worrying.

Increased Tasks and Roles

Many of the siblings described carrying out more household and care tasks as a result of their ill sibling’s condition. For instance, participants made statements such as, “I have to make sure (the ill child) takes his pills every day,” and “I help around the house.” In completing tasks of caregiving and household maintenance, participants described fulfilling roles which exceeded their developmental level or role as a ‘child’ in the family. For instance, several siblings adopted the role of advocate: “I tell my mom to back off when (the ill child) has had enough,” and enforcer: “I’m the one to make him take his pills. I tell him all the time, have you taken them?!” Others described being a defender: “I stick up for him when others make fun of him,” and nurse: “I look after him at home because my mom’s at work.” Others described being counsellors: “She talks to me when she’s upset, and I listen to her and tell her it will be okay.”

Several participants described their parents often needing help with household maintenance tasks, some of which were provided by healthy siblings: “I help out by doing the cleaning.” Healthy siblings also carried out tasks of caregiving such as administering medications or preparing meals or snacks for the ill child, and several regularly supervised the child with ESRD. Older participants (ages 11 to 18 years) often described regularly caring for their ill sibling, and restricting behaviours that risked the health of the ill child, or as one participant stated, “I make sure that (the child with ESRD) does nothing to hurt his (transplanted) kidney.”

At school, several participants similarly described an ongoing vigil of watching out for their ill sibling, and his/her interactions with other children. Several felt highly responsible, and as one sibling stated, “I’m always watching (the ill child) out of the corner of my eye, at home and at school, always.”

Several participants described providing comfort, companionship, practical care such as bathing and feeding, and/or giving encouragement to the ill child when in hospital. One participant, an older sister, said that her ill sibling sometimes, “wants only me in the hospital so I go in and stay with him.” In this case, the older sister would become a surrogate caregiver in the hospital, while her parents continued to work at their jobs during the day. To do this, the healthy sister had to take time off school which she reported to have an adverse effect on her grades.

In this small sample, gender differences in the healthy sibling or the ill child did not seem to relate to the amount or type of tasks that were conducted by the sibling. However, gender and family role-related justifications were often used to explain sibling’s extra responsibilities for task-completion. For instance, several girls stated that because they were the daughter/sister (or in several instances, “the only sister,” or, “the only girl in the family,”) they were understandably encumbered with extraordinary tasks within the family. Similarly, several boys stated that as the son/brother, or as one participant stated, the “big brother (to the ill child),” it was expected that they “do more” in the family. Other elements that seemed to favour extraordinary service within the family included: (i) increasing age, (ii) the expectations of parents (for instance, “my mom tells me to look out for my sister,”) and (iii) the lack of availability of parents for caregiving/household tasks (for instance, “I do a lot with (the ill child) because my mom is busy at her job.”)

When asked how the roles and tasks they performed impacted on their daily lives, several siblings described deteriorating grades in school, and some felt they had become, in one participant’s words, more mature than similar-age peers: “I think that I don’t act and think like most people my age. This has made me grow up faster." Several participants felt that having a sibling with ESRD, and the extra care and work it necessitated in their lives, had taught them to be less focused on themselves. Several felt that this had helped them, but most also described it as "tough" or "hard." Several participants described themselves as being "left out" of the desired amount of interaction with or attention from their parents, and some noted that because of their responsibilities in the family, they were "left out" of many desirable leisure activities with peers.

Feeling "Left Out"

Participants commonly stated that, relative to the child with ESRD, the healthy sibling was less often the focus of parents' primary concern and attention. The health of their ill sibling, by virtue of its ongoing vulnerability and uncertainty, took precedence in the family, yet it also limited siblings' participation within the central issues of the family. Almost all siblings commented about the disproportionately greater amount of time that their mother devoted to the ill child due to the need for attendance at clinics and hospital, and/or special care required at home. Although most understood the need for this disproportionate amount of maternal attention, they described sometimes feeling "left out" or "alone," and in some cases, resented having to miss out on comparable time with and attention from their mothers, or what one participant termed, "special times with my mom."

Participants who knew little about their sibling's ESRD, or the purpose of treatments (often younger participants) sometimes viewed clinic appointments and hospital admissions as their ill sibling's "time away with mom," and frequently did not identify these occasions as necessarily difficult, imperative or purposeful for the child with ESRD:

> I think when they go to the hospital, they play in the playroom a lot. I wish I could go too.
>
> When my mom and (the ill child) go in for clinic, they always spend the day shopping. I never get to do that.
>
> I have to go to school when my dad and (the ill child) go for blood work. I know they have fun . . . sometimes go to the mall.
>
> But I have to just go to school. I never get to miss because I'm not sick.

Siblings with very limited knowledge about ESRD based their understanding of the illness and treatment on a fragmented awareness of the condition, and often made presumptions based largely on what they witnessed, or on remnants of information that had been told to them by parents or the ill child. Since they were seldom with their ill sibling in hospital, healthy siblings' understanding of activities during hospitalization was often incomplete and distorted. One sibling said that she only heard about the "fun stuff at the hospital like the play room or the clown." In other cases, parents were reported to sometimes explain ESRD or acute illnesses/complications in ways that, as once participant stated, "made it easier to take, the bad news that is." Several participants, however, stated that despite and in some cases, because of this presumably overly-optimistic presentation, they lacked vital information, and felt uncertain about what would happen to their ill sibling.

A paradoxical reality was thus described by many siblings. Although often more involved in day-to-day activities of caregiving and household management, they often felt increasingly distant from the core of family priorities and foci of concern: the condition of the ill child. Several siblings profoundly regretted and in some cases, resented, feeling "left out" of this central place in the family:

> I feel alone all the time in my family. I hate that. I don't like always being the one that really doesn't know what's going on. The most important thing for my parents is (the ill child) because he's so sick so much. I wish I was included.

Altered Peer Relationships

Several healthy siblings described altering their relationships with peers after the diagnosis of ESRD. Others, whose sibling had had ESRD for a long period of time (for instance, since the healthy sibling's birth), described unique peer relationships which had been influenced by their sibling's ESRD. For example, relationships had been influenced by peers' treatment of the ill sibling. Several described "cruel" or "mean" comments by peers directed at the ill child. For the healthy sibling, this often precipitated an end to his/her relationship with the peer. In a few cases, healthy siblings had become involved in verbal or physical altercations to express their anger and/or defend their sibling: "I got mad and beat him up, and I got beat up—after he said how stupid my brother looks . . . It was a mean comment made by a bully. I can't stand that." An adolescent girl ended a relationship with a boyfriend because the boyfriend could not understand that she needed to spend more time at home caring for her ill brother.

Conversely, some participants described choosing friends who were understanding of their sister/brother's condition, needs and differences, and hence, were kind to their ill sibling. Several stated that these friends tended to be more patient about healthy siblings' restricted availability for socializing, and in some cases, engaged in social activities in the home—such that the healthy sibling could socialize with peers while also caring for the child with ESRD. For instance, one participant who had carefully selected her friends commented:

> My friends are kinder to (the ill child) than I am. I think they understand him more than I do, and are more patient when he's in one of his moods. They come over to my house and we watch T.V. or videos together because they know I have to be home with (the ill child). They do things that they know he can do, and are really good to him so he loves it, and for me, I get to be with my friends.

Most participants were satisfied with the quality of their friendships, and in some cases, participants thought that their friends' interest and support had fostered closer relationships. However, several participants also identified factors that limited their friendships. These included increased responsibilities emerging from their sibling's condition, and healthy siblings' need to more frequently be in the home helping. Also, in a few instances, participants stated that they were "no fun" or "too sad" or "always worried," and therefore looked to themselves as a cause for having fewer friends.

Worry

Several participants expressed concern and/or worry about their sibling with ESRD. One participant described, "secretly worrying," which she defined as thinking a lot about the problems in the family (including ESRD). Yet, like several other siblings, she seldom expressed these worries to others in the family in order not to exacerbate what she viewed as "already too much tension and worry." Expressing her worries, she thought, unnecessarily risked increasing family stress, hence her worries remained hidden and unaddressed.

The extent of worry felt by participants seemed to be associated with the strains imposed by ESRD and personality issues of particular siblings. Siblings seemed less worried when they had been given enough information about their sibling's ESRD in an age-sensitive manner:

> My mom and dad make a point to be honest with me. When I was younger, they were honest about everything (about the ill child's condition and treatment), but I don't think they told me as many details. That was good because I needed to know (about ESRD) . . . but I might have had trouble with too much . . . gory, scary detail to scare me. But still, they told me honestly what was happening, and they always told me that no matter what happened, they would be there for me.

As this participant reminisced, she appreciated information that was shared openly, but also in a sensitive, affirming and age-appropriate manner. Several other participants who were well-informed about their siblings' condition similarly valued this information; described less worry; and felt that they could deal with their worries by drawing on their knowledge and awareness, "Because I know about the disease, it's not so hard for me. My mom tells me honestly, so that makes it a lot easier."

Conversely, participants with little information about their ill sibling's condition often worried about what they presumed or imagined might happen to the ill child. Their worries were sometimes based on inaccurate presumptions, or fears that might have been eased through discussion with informed and caring persons. For instance, an 11 year old boy confided about his largely unarticulated worry and fear that his brother might die, "Until he gets a transplant, I worry that he could die . . . Yeah, I wonder a lot if he'll die. But I never say that to anybody, and we never talk about that in my family."

Participants described coping with their worries in different ways. Some said they thought about other things, and one said that he, "dreamed about being in a different family." Another participant stated that he "would love to get away," but knew that he was needed in the family. Several participants had become involved in school or other activities that, they thought, diverted them from worries or problems in their family. Others described talking with parents, grandparents or friends—stating that they found comfort and reassurance in these interactions. Some participants described developing a positive or an accepting attitude: "I've just learned to accept things as they come," and others viewed their struggles as "normal" which, in turn, helped them perceive their life as not unusually difficult or problematic: "My family and my problems? It's just the way it is, not unusual. I just don't think about any of this as strange, and then it's alright."

Using these various strategies, healthy siblings persevered and interacted within their families and social worlds. Most felt that they were effectively managing their daily lives and the challenges they faced, and most stated that overall, they enjoyed their lives.

DISCUSSION

Participating siblings of children with ESRD conveyed many issues of concern as well as strategies in adapting and responding to their life of increased responsibilities, adjustments, and worries. Many siblings struggled with the unique demands on them, but several also felt that their siblings' ESRD had enriched their lives. Several felt proud about their level of maturity and helpfulness in the family, and attributed these achievements to the responsibilities and expectations associated with their ill sibling's and family's needs.

Yet, findings also clearly illuminated many difficulties encountered by healthy siblings in the course of their daily lives. There is clearly a need for greater understanding of the challenges encountered by healthy siblings. School attendance and performance sometimes suffered. Time with peers was often limited by the care needed by their ill sibling, as well as participants' increased involvement in household duties. Most felt that they had less time for "play," and received less attention from their parents than did their ill sibling. Participants' lives thus appeared to exist at the nexus of pressing challenges, yet also personal strengths and intuitive strategies in addressing these challenges.

Effective family communication and the conveyance of timely information to healthy siblings appeared beneficial to participants. A sense of personal mastery and control over siblings' own lives emerged as siblings felt "part" of the ill child's condition/care. This did not necessarily mean being involved in the work of caring for the ill child (although many siblings were involved in this care) or burdened with parental worries or fears, but rather comprised being well informed about details of treatments, symptoms, complications, and hospitalizations. It seems, from these preliminary findings, that a clear understanding about ill siblings' condition allays fears, and contributes to positive adjustment.

Based on these findings, the ongoing process of sharing ESRD-related information with healthy siblings is beneficial to the extent that information is clear and age-appropriate, and siblings' questions are answered honestly and sensitively. Some siblings may need to be encouraged to raise their concerns and questions, particularly if they believe that this will create increased and/or unmanagable family stress.

In fostering increased information-sharing with healthy siblings, health care professionals have the potential to assist and support parents and healthy siblings in the difficult tasks of explaining and disseminating information in an open, age-appropriate and sensitive manner. Health care professionals can contribute in several ways: (i) offering education and support to parents and families; (ii) assisting healthy siblings in understanding and coping with illness-related information; and (iii) providing interventions and resources which aim to stimulate family discussion, support and information sharing. For instance, the facilitation of family meetings in clinical settings may be beneficial for some families. Awareness and a sense of support and connection for siblings could be encouraged by peer support offered through groups or computerized network 'chatlines' available for siblings of children with ESRD or other chronic illnesses.

Advocacy is also needed. Resources must be found which target family needs and strengths, and free enough of caregiving parents' time to allow them to share information and attend to the developmental needs of their healthy children. Resources such as respite care for the child with ESRD could permit more parental availability for healthy children, and reduce dependence on these healthy children for inappropriate involvement in caregiving and household tasks.

These implications invite research, policy and practice that extend health care to the holistic strengthening of families. Conceptual models of the family with chronic illness must be developed that recognize the complexity of needs and strengths, rather than obscuring the realities of healthy family members. Accordingly, the developmental needs of all children, not only the child with ESRD, must be considered. Health care professionals are well placed to act as a resource for families, and actively to support siblings in optimizing their quality of life.

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CNSW ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION'S 2005 SPRING CLINICAL MEETINGS

RACIAL DIFFERENCES IN KNOWLEDGE AND ATTITUDES ABOUT DIABETES AND ORGAN DONATION

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Since African Americans and Hispanics are twice as likely to have diabetes and kidney disease compared with Caucasians, we explored whether their attitudes about diabetes and organ donation statements varied by race. Using random-digit dialing oversampling minority households, we surveyed 1,416 African-Americans (30%), Hispanics (10%), and Caucasians (60%) in Missouri (mean age: 45 years, 59% female). Most respondents had income levels between $26,000-$50,000 (38%) or $10,000-$25,000 (24%). Their overall health care satisfaction was high [mean= 6.1 on a scale from 'very dissatisfied' (1) to 'very satisfied' (7)], with no significant differences due to race. After adjusting for disproportionate sampling using data weights, we conducted chi-square analyses comparing relevant attitudes by race.

Both African Americans and Hispanics felt that more diabetes education in their communities was needed compared to Caucasians (AA: 91% vs. 85%, x^2=9.82, p<.002; HSP: 91% vs. 85%, x^2=3.67, p<.05). They both did not understand that diabetics should not smoke (AA: 87% vs. 91%, x^2=4.82, p=.03; HSP: (72% vs. 91%, x^2=38.79, p<.001)) and that dialysis is a possible complication of diabetes (AA: 65% vs. 74%, x^2=11.04, p=.001; HSP: 63% vs. 74%, x^2=6.55, p=.01). Compared to Caucasians, Hispanics were significantly less likely to: believe that health care professionals related well to them (68% vs. 56%, x^2=6.64, p=.01), avoid the doctor to avoid learning if something was wrong (65% vs. 27%, x^2=78.51, p<.001) and believe that diabetes complications were inevitable (50% vs. 38%, x^2=6.92, p=.01). African Americans were also less interested in donating their organs upon death (37% vs. 66%, x^2=95.13, p<.001) or through living donation (85% vs. 90%, x^2=6.88, p=.01) than Caucasians.

To reduce health disparities, tailored health education correcting diabetes misinformation and emphasizing the importance of organ donation needs to be made accessible to these communities.

COMPUTERIZED ADAPTIVE ASSESSMENTS OF HEALTH-RELATED QUALITY OF LIFE AMONG HEMODIALYSIS PATIENTS

Anastasia E. Raczek[1], John E. Ware, Jr.[1], Klemens B. Meyer[2,3], Michelle M. Chapman[2,3], Asha P. Masurekar[3], Renee N. Saris-Baglama[1]. [1] QualityMetric Incorporated, Lincoln, RI, USA; [2] Tufts-New England Medical Center, Boston, MA, USA; [3] Dialysis Clinic, Inc., Boston, MA, USA.

Patient-reported assessments of health-related quality of life (HRQOL) are essential for understanding disease burden and treatment benefit. However, most assessment tools are impractical for routine use and do not meet clinical standards of precision. To address these issues, in an NIH-funded study we used item response theory (IRT) and computerized adaptive testing (CAT) methods to develop prototype software (CKD-CAT) for measuring three HRQOL domains of importance in kidney disease (Effects of Kidney Disease, Sleep Functioning, Bodily Pain) and field-tested it in a sample of hemodialysis patients (N=49) undergoing treatment. A 63-item static survey and the CKD-CAT were completed in random order and results were compared. CAT administrations achieved comparable score precision with fewer items (M=15.2, SD=1.5) and a significant reduction in administration time (M=6.62 min, SD=4.88 vs. M=14.08 min, SD=6.64). Patients preferred the CKD-CAT (57%) over the static survey (25%) but many had minimal or no previous computer experience and instinctively touched the computer screen to indicate their responses to items. A tablet touch screen PC was easier to use than a laptop with a hand-held mouse, which frequently got entangled with patients' dialysis tubing. We conclude that the use of IRT and CAT technology is likely to yield practical and precise assessment of HRQOL if patient interfaces are customized to meet the needs of the specific population and setting. Further development of the CKD-CAT is planned to broaden its application to all patients with CKD regardless of disease severity and treatment modality. The resulting tool will allow clinicians to routinely measure HRQOL, with the precision required to assess change in HRQOL with kidney disease progression, and to apply its results to patient care.

THE FLUID ADHERENCE PROJECT: THE INFLUENCE OF SOCIAL WORK INTERVENTION IN HEMODIALYSIS

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Excessive fluid gains among hemodialysis patients continue to concern renal professionals. Excessive fluid gains often lead to cardiac complications and uncomfortable treatments (e.g., cramping).

This single subject design examined the influence of social work intervention on a patient who experiences consistent excessive fluid gains. The patient received two 16-ounce water bottles and was instructed to fill each water bottle each morning with two drinks reasonable to his renal diet. The patient was instructed to drink no more than the 32-ounce total per day for a duration of two weeks. Social work interventions included a calendar for daily reminders, ongoing encouragement, and a small incentive to complete the project.

The average pre-weight for the patient two weeks prior to the project was 170 pounds. During the two weeks of the project the patient's average pre-weight decreased to 167.7. This was an average decrease of 2.3 pounds for this patient over a two week period, with a weight differential (+/-) of 1.5 pounds. The patient's dry weight of 161 remained constant. It did not change at any point two weeks prior to the project or the two weeks of the project.

This study offers several implications for social work practice. It promotes future research using similar projects with more patients. It encourages renal professionals to look at how other variables such as blood pressure and treatment complications are affected by a decrease in fluid gains. Additionally, this study emphasizes the importance of consulting with a multidisciplinary team when assessing biopsychosocial factors of patients. Social work intervention with hemodialysis patients can encourage lesser fluid gains.

National Kidney Foundation®
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Council of
Nephrology
Social
Workers

CNSW RESEARCH GRANTS PROGRAM

Purpose

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

Areas of Interest

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

Eligibility

Grant applicants must meet the following eligibility requirements:

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

Grant Requirements

Each grant recipient is responsible for:

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

Funding

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

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

How to Apply

If you are interested in preparing a proposal, please submit a letter of intent to the CNSW Research Grants Program, National Kidney Foundation, Inc., 30 East 33rd Street, New York, NY 10016 by December 15, 2005. The letter of intent must include the following:

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

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

Review Schedule

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

Further Information

For more detailed information or to be put in contact with a research "mentor" contact Sally Rice by e-mail: srice@kdp01.kdp-baptist.louisville.edu

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