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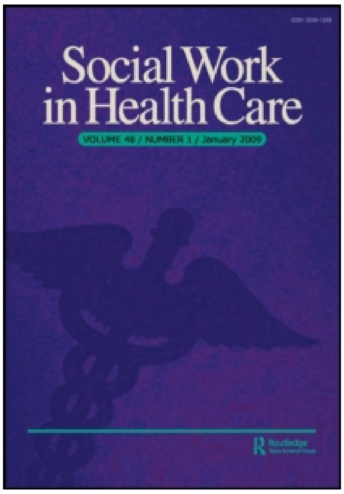

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Dialysis Patient Characteristics and Outcomes

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Dialysis Patient Characteristics and Outcomes: The Complexity of Social Work Practice with the End Stage Renal Disease Population

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SUMMARY. This article describes a demonstration project designed to explore psychosocial risk and resiliency factors, social work interventions and health-related outcomes with dialysis patients. The study is unique in including an interdisciplinary research team to guide the process, using available data contained within the medical record and focusing on interventions and outcomes over time rather than at one or two

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points in patients' treatment histories. It demonstrates the complexity of practice with dialysis patients and the crucial role for social workers in enhancing patient outcomes. Secondary benefits of this methodology and implications for social work practice and research are discussed. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: <getinfo@haworthpressinc.com> Website: <http://www.HaworthPress.com> © 2001 by The Haworth Press, Inc. All rights reserved.]*

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Measuring patient outcomes has become especially crucial in the competitive world of healthcare where patient outcomes are studied in relation to medical and cost effectiveness (Epstein, Zilberfein, & Snyder, 1997; Nurius & Vourlekis, 1997). For patients with End Stage Renal Disease (ESRD), understanding and reporting on the interconnection between dialysis patient characteristics and outcomes can inform social workers' interventions and advocacy efforts in support of continued, federally mandated involvement of professional social workers with this population. Because psychosocial factors have a strong influence on how patients progress on dialysis (Vourlekis & Rivera-Mizzoni, 1997), and social work interventions can affect patients' psychosocial situation (Furr, 1998), social work services are critical to positive outcomes among the ESRD population.

This article describes a demonstration project funded by the National Kidney Foundation's Council of Nephrology Social Workers (CNSW) and is designed to employ "clinical data-mining" (Epstein, 1998) to explore the association of psychosocial risk and resiliency factors, social work interventions and adherence and other health-related outcomes among hemodialysis and peritoneal dialysis patients. In doing so, it demonstrates the complexity of social work interventions with dialysis patients and the crucial role for social workers in enhancing patient outcomes.

DEMOGRAPHIC AND PSYCHOSOCIAL FACTORS AND HEALTH-RELATED OUTCOMES AMONG DIALYSIS PATIENTS

A substantial literature centers on the interplay between demographic and psychosocial characteristics and ESRD outcomes. Much of this literature focuses specifically on adherence because of its obvious relationship to ESRD patients' morbidity, mortality and overall quality of life. Measurements of compliance generally focus on adherence to: (1) restrictions in diet and fluid intake; (2) the medication regimen; and (3) treatment appointment schedules (Bame, Petersen, & Wray, 1993; Brownbridge & Fielding, 1994; Christensen, Benotsch, & Smith, 1997; Davis, Tucker, & Fennel, 1996; Furr, 1998; Kaplan De-Nour & Czaczkes, 1972; Kimmel et al., 1998; Leggat et al., 1998; McKevitt, Jones, Lane, & Marion, 1990). Family and social support (Boyer, Friend, Chlouverakis & Kaloyanides, 1990; Burton, Kline, Lindsay, & Heidenheim, 1988; Davis et al., 1996; Kimmel et al., 1998; Levenson & Glocheski, 1991; O'Brien, 1990), demographic characteristics (Bame et al., 1993; Christensen et al., 1997; Davis et al., 1996; Leggat et al., 1998), and psychological variables (Brownbridge & Fielding, 1994; Kaplan De-Nour & Czaczkes, 1972; Kimmel, Wiehs, & Peterson, 1993; Levenson & Glocheski, 1991) are among many factors associated with patient compliance. Other studies focus on outcomes such as quality of life (Kutner & Brogan, 1990; Kutner & Brogan, 1994; Wolcott, Nissenson, & Landsverk, 1988; Killingworth & Akker, 1996) and general health status (Ozminkowski, White, Hassol, & Murphy, 1997). Finally are articles which attend to the kinds of interventions that health care providers, including social workers, can use to enhance outcomes among renal patients (Furr, 1998; Gorman & Anderson, 1982; Hener, Weisenberg, & Har-Even, 1996; Homedes, 1991; Kirschenbaum, 1991; Streltzer & Hassell, 1988; Vourlekis & Rivera-Mizzoni, 1997).

This study is unique in focusing on an urban, low-income, minority population; in employing an interdisciplinary research team to guide the research process; in retrospectively reviewing available data contained within medical records; and in focusing on interventions and outcomes over time rather than at one point in patients' dialysis history.

THE SETTING

The study project took place at Mount Sinai Hospital, a large, urban academic medical center with approximately 950 inpatient beds and a comprehensive ambulatory care division. The Hospital is surrounded by very diverse neighborhoods, from middle-class and wealthy to its catchment area that includes a very poor, largely Latino community. The study focused on patients at two dialysis sites: one that is hospital-based and includes approximately 35 hemodialysis and 65 peritoneal dialysis patients, and a nearby satellite unit that has capacity for 190 hemodialysis patients.

THE STUDY POPULATION

The study population consisted of 100 adult hemodialysis and peritoneal dialysis patients who (1) began dialysis between December 1, 1996 and April 1, 1998 *and* (2) received at least two months of outpatient dialysis at either of the sites. Only those who had been dialyzed on an outpatient basis for at least two months were included because, in general, after two months of outpatient dialysis, patients would be assumed to be medically and psychosocially stable and to have received some education and training regarding the treatment regimen. Therefore, it was presumed that medical and psychosocial outcome measures would have increased stability. Eight patients' medical records were unable to be located and they were therefore not included in the study. All other patients who met these criteria were included until the sample numbered 100 patients. (Approximately five other patients met the criteria.) The sample was limited to *100* patients to facilitate data collection and analysis of findings in this demonstration project.

METHODOLOGY

Using Available Clinical Information

The methodology for the project parallels an approach successfully employed at Mount Sinai Hospital, utilizing routinely available patient chart information to study retrospectively psychosocial risk factors and treatment outcomes among liver transplant patients (Epstein et al., 1997). A retrospective methodology using available data has several advantages:

1. It is less intrusive to patients and staff than questionnaires administered directly to patients. Daily patient care routines are less likely to be disrupted when data collection focuses on available medical record documentation rather than direct contact with patients (Epstein et al., 1997).

2. The problems presented by a potentially low response rate and the time involved in administering a questionnaire to patients can be avoided and data can be gathered more quickly.
3. Data is potentially more agency and practice relevant because it is generated from actual documentation by the medical and social work team (Epstein et al., 1997).

The Interdisciplinary Research Team

The interdisciplinary research team guiding the process included: the medical director of Mount Sinai Hospital's on-site dialysis unit, the unit's nurse manager, three Masters-level renal social workers with a combined experience of nine years with dialysis patients, a renal nutritionist and the author who is an Assistant Director in the Department of Social Work Services with clinical and supervisory experience in nephrology social work. A research consultant from Hunter College School of Social Work who facilitated the liver transplant study was consultant to the team throughout the project. The team met periodically throughout the study and focused on establishing the study population, developing the data collection instrument, planning for data analysis, analyzing and interpreting the findings. The purpose of involving an interdisciplinary team, including social workers, throughout the research process was that it would enhance cohesiveness among them; provide clarity as to professional decision-making, roles and practice; and would enhance the validity of the study instrument and outcomes (Ben Shahar, Auslander, & Cohen, 1995; Epstein et al., 1997). Moreover, the credibility of the findings would be especially enhanced since this process captures the medical and psychosocial perspectives of staff actually caring for dialysis patients.

The Data Collection Instrument

A quantitative data collection instrument from the liver transplant study was revised by the research team to reflect psychosocial determinants, social work interventions and outcomes relating to ESRD patients. Altering an existing instrument that had been successfully implemented in a previous study was more time- and cost-efficient than developing an entirely new one for this study. In addition, use of the instrument will facilitate comparison and replication in the future at other sites.

The instrument measures three sets of variables:

> *Independent variables*: from medical record demographic information and initial medical and psychosocial assessments. They include demographic data; psychosocial factors (e.g., employment history, living situation); and medical information (e.g. co-morbid conditions, time on dialysis).
>
> *Intervening variables:* include interventions performed by social work staff in order to address patients' presenting problems and documented in initial psychosocial assessments, ongoing progress notes and patients' care goals. Examples are individual, family and group counseling and referral for benefits and community-based services.
>
> *Outcome variables:* adherence and other medical and psychosocial outcome measures obtained from available data such as ongoing medical and social work progress notes and patient care goals. Examples include missed treatments, emergency department visits, hospitalizations, and ability to perform activities of daily living (ADL's).

The data collection instrument identified patients through a code number so that patient confidentiality would be assured.

In addition to making the instrument ESRD relevant, other important revisions to the liver transplant instrument were made to enrich the research findings. First, the liver study had focused on data on patient obstacles to coping with transplant. In the dialysis study, resiliency factors to assist coping capacity were also captured. Social workers and other team members then benefit from knowing about both the problems that affect managing the illness *and* the strengths patients bring that can be reinforced (Barnard, 1994; McCubbin, McCubbin, Thompson, Han, & Allen, 1997).

Second, rather than collecting data at two points in time as had been done in the liver transplant study, social work interventions and outcome measures on the dialysis data collection instrument were divided into quarters to reflect more accurately patients' medical and psychosocial history. Data were collected beginning with the first outpatient dialysis treatment and collected for every quarter in which the patient received treatment. Since length of time on dialysis has been shown to be a significant predictor of compliance (Boyer et al., 1990; O'Brien, 1990), other outcomes can also be expected to differ according to how long patients have received treatment. It was hoped that designing the instrument to capture data at quarterly intervals would provide a more comprehensive picture of the complexity of the experience of being on dialysis over time and thus strengthen the findings and their practice implications.

Data Collection

Data was collected from March-July, 1998 by four social workers who were presently working or had previously worked at the dialysis sites. Benefits of including social workers practicing with renal patients as data collectors include: (1) enhanced validity and reliability since the data collectors knew the patients and families well and were intimately involved in the myriad medical and psychosocial issues they presented (Epstein, 1998); (2) time efficiency since the social work staff knew where variables in the medical record were recorded, and therefore, spent minimal time searching for data; (3) heightened commitment to the project since three of the social workers were also part of the research team and therefore were involved from conceptualization through data analysis.

The instrument was initially piloted to promote its reliability. To do so, all the social workers collected data on the same patient and then met to compare results. In general, there was agreement on most responses. When there were differences, they were resolved through discussions among staff. These meetings were also used to clarify any additional confusion about the instrument. Decision-making rules for data extraction were then formulated.

Data Analysis

Using SPSS, univariate and bivariate analysis was done of patient characteristics, social work interventions, and patient outcomes. Analysis focused on associations among demographic, psychosocial and medical factors and compliance and other health-related outcomes as well as detailed descriptions of the complex interventions used by social workers in working with dialysis patients and their families over time.

FINDINGS

Patient Characteristics

Demographics: Table 1 describes the demographics of the study population at the time of the social workers' initial psychosocial assess-

TABLE 1. Patient characteristics

		%			%
Gender	female	57	**Lives with**	Child	51
	male	43		Spouse	32
Age *(mean 54)*				Other	19
	Less than 40	23		Parent	12
	40 through 65	48		Sibling	12
	More than 65	29		Other relative	8
				Significant other	6
Ethnicity	African-American	44		Home attendant	5
	Latino	34		Friend	2
	Caucasian	15			
	Other	6	**Insurance**	Medicaid	64
				Medicare	49
Marital Status	Never married	26		Private insurance	23
	Married/common	25		Other	3
	law			Uninsured	2
	Separated/divorced	22			
	Widowed	20	**Primary Language**	English	75
	Other	2		Spanish	16
				Other	5
Lives alone		37			
			History of Employment		72
			Employed at Assessment		10
			Resumed Working		13

ment. The population is racially and ethnically diverse and primarily low-income. Although a little over a third (37%) live alone, of note is the fact that about half (51%) of patients live with a child (either adult child or younger) and almost a third (32%) with a spouse. Also noteworthy is the fact that although 72% have a history of employment, only 10% are employed in the initial days of treatment. Only 13% of patients who had previously worked resumed employment once they began dialysis treatments.

Resiliency factors and impediments affecting coping: Table 2 enumerates resiliency factors and impediments to coping cited in patients'

TABLE 2. Resiliency factors and impediments affecting coping

	%	
Resiliency factors		
	69	Support by family/friends/caregiver
	48	Good family relationships
	27	Adequate physical functioning
	21	Ability to understand ESRD/treatment
	18	Cultural religious/spiritual beliefs
	17	General ability to cope with adversity
	16	Other
	9	Employment/student status
	8	Ability to maintain compliance
	7	Ability to cope with multiple medical illnesses
	3	Financial status
	1	Insurance status
	1	Adequate housing
	11	No strengths noted
Impediments		
	28	Coping with ESRD
	24	Other
	23	Poor physical functioning
	16	Coping with multiple medical illnesses
	13	Financial
	12	Insurance
	8	Lack of understanding of ESRD/treatment
	8	Mental health problems
	7	Coping with compliance requirements
	7	Lack of support by family/friends
	6	Bereavement
	5	Housing
	3	Poor family relationships
	2	Divorce/separation
	2	Substance abuse
	2	Language barrier
	1	Impact of cultural/religious beliefs on treatment
	1	Coping with other family member's illness
	0	Sexual problems
	0	Employment/student status
	21	No problems noted

initial psychosocial assessments. Resiliency factors are indicators of patients' strengths that helped them manage ESRD while impediments are factors that hindered coping. These factors were developed from the renal social workers' practice and from their knowledge of regularly documented patient strengths and problems. Thus, the predominant resiliency factor was support by family and friends (69%) and good family relationships (48%). Although many patients in this population had a general ability to cope with illness and adversity, in the social worker's initial assessment over a quarter (28%) were having a general difficulty coping. Among approximately a quarter (24%) of the patients, a range of impediments listed in the "other" category included a variety of psychological, cognitive and resource issues such as memory problems, anxiety, and lack of adequate transportation and home care services. No apparent strengths were noted in 11% of initial assessments, while in 21% of assessments, no impediments were noted.

Patient anxiety, depression, and need for assistance with ADL's: Table 3 demonstrates that in the first 3 months of patients' dialysis experience, many were assessed by social workers as being anxious and depressed. Thus, in the first quarter, 52% of patients were noted as anxious and 43% depressed. Although the percentage decreases over time, anxiety continued to present a problem for 30% of patients even after 10 months of treatment. In all quarters, about half of this population had need for some assistance with ADL's either from family members and friends or from formal home care services.

Social Work Interventions

Nephrology social workers provide psychosocial assessment, counseling and referral to community services to assist patients on dialysis and their families (American Kidney Foundation, Council of Nephrology Social Workers, 1993). In the study population, 57% received social work counseling in the first three months of outpatient treatment. Although the degree to which social workers counseled patients declined over time, approximately a third (32-37%) of patients were receiving counseling in any one quarter in the first year of treatment. According to patient records, only 9% of family members received counseling in the first quarter with only a slight rise to 11% in months 4-6. (The questionable validity of this finding will be discussed later in the paper.)

In relation to the content of social work counseling, not surprisingly, patients often talked about issues directly related to being on dialysis,

TABLE 3. Percentage of patients experiencing anxiety/depression/assistance with ADL's by quarters*

	Months			
	1-3	**4-6**	**7-9**	**10-Present**
Anxiety	**52** *(N = 90)*	**30** *(N = 89)*	**25** *(N = 58)*	**30** *(N = 39)*
Depression	**43** *(N = 88)*	**18** *(N = 90)*	**17** *(N = 58)*	**10** *(N = 38)*
Some assistance	**51** *(N = 95)*	**51** *(N = 78)*	**51** *(N = 51)*	**47** *(N = 34)*

*Excluding non-applicable/missing data/no notation

especially in the first few months of treatment. Thus, in the initial three months of treatment, almost three quarters (72%) of patients focused on coping with their diagnosis and treatment and slightly over a quarter (26%) discussed this topic in months 4-6. Other topics discussed in the first months of dialysis included: how to cope with multiple medical illnesses (43%), decreased physical functioning (39%), mental health issues such as feelings of anxiety or depression (39%), difficulty understanding the ESRD diagnosis (32%) and how to maintain compliance with the treatment regimen (22%). Patients also focused on concrete issues: 38% in the first quarter focused on coping with insurance problems while 29% were concerned about financial issues. Over half (51-57%) of family members whose social work counseling was documented in the medical record in the first two quarters talked about their lack of understanding of ESRD treatments while 36% initially discussed how to cope with the patient's diagnosis and treatment. Similarly to patients, families also discussed more concrete issues: almost a third (31-32%) were having difficulty coping with financial problems in the first six months of treatment.

In addition to counseling, nephrology social workers provide assistance to patients and families through referral for community resources and benefits. Assistance was most frequently provided in the first quarter of treatment and often centered on referral to obtain government or work related benefits, insurance, transportation and home care services.

Non-Adherence Indicators

Table 4 highlights the extent of non-adherence among this population. For hemodialysis patients, at least a quarter missed their hemodialysis treatments a minimum of once per month in the first three quarters of outpatient treatment, increasing to 44% of patients in the fourth quarter. Patients also frequently asked to be taken off the hemodialysis machine early, with more than a third exhibiting this behavior in any of the four quarters. Although these behaviors may be associated with non-compliance, there are also other reasons that patients request an early end to treatment; for example, some experience painful leg cramps. Nonetheless, in relation to non-compliance with diet among hemodialysis and peritoneal dialysis study patients, a large majority (76%-85%) were assessed by staff as failing to follow the prescribed diet regimen.

Patient Characteristics, Presenting Problems and Non-Adherence Outcomes

Bivariate analysis was done to explore the association of patient characteristics and the following outcomes (occurring at least once over four quarters): (1) emergency department (ED) visit(s); (2) hospitalization(s); (3) missed hemodialysis treatment(s); (4) asking to be taken off hemodialysis machine; (5) weight gain between treatments (hemodialysis) or between physician visits (peritoneal patients). Although ED visits and hospitalizations can result from a variety of factors, they were viewed as negative patient outcomes. Only those practice relevant patient characteristics that are either closely or significantly associated ($p < .05$) with these outcomes will be discussed.

ED visits: Educational level and poor physical functioning were associated with patients coming to the ED at least once within the four quarters in which data were collected. Hence, patients with lower educational levels were more likely to go to the ED. More specifically, 61% of patients with a high school degree or less visited the ED as compared with 31% of those with at least some college experience (Chi-square = 7.159, df = 1, $p < .01$). Not surprisingly, 61% of patients with poor physical functioning as identified in their initial psychosocial assessment had at least one ED visit compared with 34% where this was not identified as a problem (Chi-square = 5.211, df = 1, $p < .05$).

Hospitalizations: Living with their child (most likely an adult child, given the age range of the population) significantly decreased chances of being hospitalized in the first four quarters of treatment. Thus, only 42% of patients who lived with a child were admitted to the hospital compared with 75% of patients who did not (Chi-square = 7.099, df = 1, $p < .01$).

TABLE 4. Percentage of patients exhibiting non-adherence behaviors by quarters*

	Months			
	1-3	**4-6**	**7-9**	**10-Present**
Missed hemodialysis treatment	**31** *(N = 79)*	**28** *(N = 73)*	**27** *(N = 44)*	**44** *(N = 25)*
Asked to be taken off machine early	**35** *(N = 79)*	**37** *(N = 72)*	**40** *(N = 42)*	**41** *(N = 24)*
Diet non-adherence	**83** *(N = 74)*	**85** *(N = 69)*	**76** *(N = 46)*	**80** *(N = 30)*

* Excluding non-applicable/missing data/no notation

Missed hemodialysis treatments: Age, Medicare status, insurance and financial problems, work status and having difficulty coping with ESRD were significantly related to whether patients missed hemodialysis treatments. In relation to age, elderly patients were less likely to miss treatments than those less than 65 years of age. Only 35% of elderly patients missed treatments at least once in any quarter in contrast to 75% of patients aged 40-65, and 61% of patients less than 40 years of age (Chi-square = 11.928, df = 2, $p < .01$). Patients without Medicare at the start of dialysis and those that initially were experiencing insurance or financial problems were more likely to miss treatments. In other words, 78% without Medicare, as compared to 41% with, missed treatments (Chi-square = 14.733, df = 1, $p < .01$). All patients who reported having an insurance problem did not attend at least one treatment in comparison to 55% who were not concerned about insurance (Chi-square = 8.876, df = 1, $p < .01$), while 85% with financial problems missed treatments in contrast to 57% who did not have financial problems (Chi-square = 3.613, df = 1, $p = .06$). Regarding work status, patients with a history of paid employment and those who were working when dialysis was initiated had a higher incidence of missing hemodialysis appointments. Hence, sixty-eight percent of patients with a work history missed treatments while only 33% who had not worked in the past missed treatments (Chi-square = 7.263, df = 2, $p < .05$). All patients working at the start of outpatient dialysis did not attend at least one treatment as compared with 57% who were not working (Chi-square = 7.000, df = 1, p < .01). Finally, 75% of those initially assessed by social workers as having difficulty coping with their disease were likely to miss treatments, while 55% not assessed as having this problem were non-compliant with their dialysis schedule (Chi-square = 3.388, df = 1, p = .07).

Taken off machine early: Insurance and financial issues were significantly related to patients asking to be taken off the hemodialysis machine at least five minutes early. Thus, 44% of patients without Medicaid (although possibly with other insurance) asked to be taken off early at least once in contrast to 12% with Medicaid (Chi-square = 12.890, df = 1, p < .01). Ninety-two percent of patients with insurance problems requested an early departure compared with 15% without insurance concerns (Chi-square = 33.801, df = 1, p < .01), while 69% of patients with financial problems at the time of initial psychosocial assessment exhibited this behavior in comparison to 17% who were not experiencing financial problems (Chi-square = 16.492, df = 1, p < .01).

Weight gain: For hemodialysis and peritoneal dialysis patients, weight gain recorded at least once between appointments, a sign of non-compliance with fluid restrictions, is associated with race/ethnic background, Medicare status and difficulty coping with multiple medical illnesses. Latino patients had the highest incidence of weight gain (44%) compared with African-American (23%) and Caucasian or other racial/ethnic backgrounds (19%, Chi-square = 5.588, df = 2, p = .06). Patients with Medicare at the start of dialysis were less likely to experience weight gain over time than those without it. In other words, 20% of patients who had Medicare gained weight between appointments compared with 37% of those who did not have Medicare (Chi-square = 3.445, df = 1, p = .06). Finally, 50% of patients who were assessed by social workers as having difficulty managing multiple medical illnesses gained weight between appointments in contrast to 25% who were not assessed to have this problem (Chi-square = 3.951, df = 1, p < .05).

DISCUSSION

The study sample is predominantly low-income and African-American or Latino, reflecting Mount Sinai Hospital's catchment area population. In relation to resiliency factors and impediments to coping, the majority of patients *do* have the familial and social supports that in other studies have been shown to buffer against depression, increase compliance and contribute to positive health outcomes (Burton et al., 1988; Christensen et al., 1997; Furr, 1998; Kimmel et al., 1998). Some patients bring to the treatment a general ability to understand their diagnosis and treatment and an ability to cope with adversity, while, in contrast, others are having difficulty coping with the crisis of being diagnosed with ESRD. For some patients, resource issues surface, such as financial and insurance problems, that negatively affect illness management. Certainly, there is an intertwining of psychological strengths and impediments along with patients' "concrete" needs that point to the multi-faceted complexity of social work practice with this population.

Most patients had documented strengths, demonstrating that social work staff are recognizing and reinforcing patient characteristics and beliefs that can contribute to success on dialysis. However, one fifth of patients' initial psychosocial assessments had no recorded apparent obstacles to coping. This finding may stem from a variety of factors: (1) patients' reticence to discuss problems when they first are interviewed; (2) patients' ability to cope with ESRD because they have experience managing other chronic illnesses; (3) the benefits of increased access to care and socialization that dialysis affords some patients (Kutner & Brogan, 1990; Kutner & Brogan, 1994); and, (4) in some instances, social workers' failure to identify problems among some patients.

Concerning patients' mental health, it is important that social workers continually monitor levels of anxiety and depression since this study and others demonstrate their prevalence among nephrology patients (Davis, Krug, Dean, & Hong, 1990; Illic, Djordjevic, & Stefanovic, 1996; Kutner, Fair, & Kutner, 1985). Because depression has especially been shown to negatively influence patient outcomes (Furr, 1998), attention to patients' psychological status is crucial. Especially in the initial months, many of these patients were experiencing anxiety and depression and, as social work researchers in our study acknowledged, counseling interventions at this time are especially intense. Although feelings of anxiety and depression lessened over time, a finding similar to Kutner et al.'s (1985), even after at least 10 months of treatment, almost a third continued to feel anxious. At the same time, social workers should also continuously assess patients' capacity to perform ADL's since approximately half of the population needed some to total assistance over the months of the study period.

In relation to work status, although almost three quarters of patients have previously worked, very few are working at the time of diagnosis or are able to resume working. Considering that so many patients are of working age, for some, their non-working status could possibly be attributed to a lack of education and skills for jobs that allow for the physical and time demands of the dialysis regimen. On the other hand, since vocational activity has been correlated with generally superior adaptation to dialysis (Wolcott et al., 1988), interventions to increase employment among this population would be an important area to work on in order to enhance patient outcomes.

Findings on social work interventions reflect the interconnection between working with patients and families to help them cope psychologically with illness and ensuring that resources are in place to help them manage the disease. Especially given that the study cohort is comprised of low-income, minority patients, many of whom experienced anxiety and depression along with more concrete financial and insurance problems, social worker interventions frequently focused on providing psychosocial counseling at the same time that referrals were made for benefits and community services. Subsequent analysis of the data in this study will focus on the impact of social work counseling on health-related outcomes such as ED visits and hospitalizations.

One of the most striking findings is the extent to which patients received counseling, particularly early in their treatment. Over the four quarters, however, the help provided by the social workers gradually decreased, possibly because as patients became accustomed to dialysis, their need for intensive counseling and resource help might have decreased. However, certainly high levels of anxiety continued as did patients' need for assistance with ADL's. Therefore, another less positive explanation for decreasing social work intervention over time may concern the need for social work staff to prioritize among their caseload. More specifically, as the volume of patients for which renal social workers are responsible increases and presenting problems become more complex (LePard, 1991), social workers might be faced with "rationing" their services. It is possible that those newest to dialysis are seen frequently to assist them in coping with treatment and ensure that adequate resources are in place. Then, as they stabilize, social workers must turn to the next round of new patients who are viewed as most in need. Social workers may do much more outreach to newer patients, while relying on those who have been on dialysis longer to ask for help as needed. Within such a context, social workers should be particularly alert to patients who may not be able to request assistance and establish mechanisms that facilitate patient self-referral. High-risk criteria can be established using the findings of this study and others so that renal team members who see patients at every treatment can refer patients who warrant ongoing psychosocial intervention.

In contrast to the high rate of patient counseling, social workers seemed to rarely counsel family members even though the impact of ESRD is so profound (Burton et al., 1988). Social workers involved in the study thought that it was likely that the number of family members who receive counseling, especially in the first months of treatment, is actually much higher than the findings indicate, but that time constraints result in incomplete recording of family contacts.

In regard to adherence, patients' difficulties following the treatment and diet regimen is considered a major problem among the ESRD population (Bame et al., 1993; Kimmel et al., 1998; Leggat et al., 1998) and is particularly disturbing since it is associated with serious medical complications and decreased survival (Christensen et al., 1997). For the study population, it is also a striking phenomenon. Among the hemodialysis population, non-compliance actually increased over time, a finding consistent with Boyer et al.'s (1990) research. In her study of long term hemodialysis patients, O'Brien (1990) argues that some experienced dialysis patients develop "reasoned" rather than "ritual" adherence (p. 209) that can actually be adaptive. In other words, patients become adept at knowing where they can "cheat" on their diet, for example, without encountering serious consequences. Leggat et al. (1998) hypothesize that patients who occasionally shorten hemodialysis treatments and are a "little bit" (p. 144) non-compliant, may benefit from gaining a greater sense of control without adverse consequences. Further analysis would be needed to ascertain whether non-adherence among this study's patients was "reasoned" or something more serious. However, renal team members might help patients to better adhere by identifying with them areas of the treatment regimen with which they *must* comply to prevent negative outcomes and where they can be a "little bit" non-compliant.

Regarding the impact of educational level on patient outcomes, Ozminkowski, White, Hassol, and Murphy (1997) found that educational level did not significantly influence general health status dimensions for ESRD patients. However, our finding that lower educational level is significantly associated with ED visits has practice implications for our social workers and other renal team members. For example, proactive steps can be taken to teach patients with lower levels of education about compliance or ways to avoid emergency medical visits. In addition, patients with less education who may not have had access to comprehensive, continuous medical care prior to starting dialysis may require direction about how to contact their physician when they have a medical need that does not require an emergency room visit. Clearly, for some dialysis patients, emergent care is necessary. Further research would be needed to ascertain the reasons behind dialysis patients' ED visits and the extent to which they are medically necessary or related to issues such as non-adherence, alcoholism or the inability to access a primary care physician (Parboosingh & Larsen, 1987; Pierce, Kellerman, & Oster, 1990).

Obviously, subsequent research would be needed to understand how living with a child is associated with decreased hospitalizations. However, an adult child who provides some amount of care to the dialysis patient and reinforces the need for adherence could possibly be a significant buffer against inpatient stays. Dialysis staff should therefore support children and other family members who assist in caring for patients and target those patients who do not have these supports to ensure that efforts are made to prevent unnecessary hospitalizations.

Although missing at least one hemodialysis treatment per quarter was prevalent across the population, elderly patients (and patients with Medicare at the time of diagnosis, a potential proxy for elderly status) were more likely to adhere to their schedule than those under 65. Other research has also found that older patients are generally more compliant (Bame et al., 1993; Boyer et al., 1990; Christensen, 1997; Furr, 1998; Leggat et al., 1998). Our study found that patients 40-65 years of age were most likely to miss treatments although younger patients also frequently did not adhere to the schedule. This finding is contrary to Leggat et al.'s (1998) that young adults tend to be the most non-compliant group on a variety of measures. Furr (1998) uses continuity theory to explain some outcome variations among dialysis patients. Thus, patients who can maintain some continuity in their previous psychosocial functioning will make a smoother adjustment to dialysis. In this context, patients under 65 may have multiple family and work related responsibilities and may be more active (Kutner & Brogan, 1990), and, therefore, find the treatment schedule especially disruptive to their lifestyle. In addition, older patients may be more accustomed to managing chronic illnesses than younger and therefore adhere more easily. Similarly, patients who had a work history and/or were working at the time of diagnosis also were significantly more likely to miss treatment. The rigid treatment regimen for this group might have been especially jarring and a likely deterrent to complete adherence.

Significantly, insurance and financial issues were found to be associated with missing treatments, being taken off the machine early, and weight gain. Patients without Medicare and those experiencing insurance and financial problems at the time that treatment was initiated were generally less adherent on these measures. It is possible that patients with Medicare represent an older or disabled population that is more experienced coping with illness and therefore more readily adjusts and adheres. Alternatively, patients without sufficient insurance and those with financial problems may represent the lower income population that other studies have demonstrated has more difficulty managing (Bame et al., 1993; Furr, 1998). O'Brien (cited in Hoover, 1989) suggests that for low-income patients, having *enough* food may be more of a priority than following a prescribed diet. Certainly, insurance and financial problems may be a predictor of non-compliance, and patients with these presenting issues should be viewed as high-risk for negative outcomes.

As expected, patients having difficulty coping with ESRD were more likely to miss treatments and patients having difficulty coping with multiple medical illnesses were more likely to experience weight gain between appointments. These findings point to social workers' accurate assessments of impediments to coping that can potentially have negative consequences. Patients having difficulty coping initially can also be identified as high-risk, requiring intensive interventions to improve their medical and psychosocial outcomes.

In relation to racial/ethnic background and adherence, Latino patients were more likely to experience weight gain between treatments than African-American, Caucasian and other patients. In a recent study of Medicare ESRD Program beneficiaries, Ozminkowski et al. (1997) found that health status among Hispanic persons was often lower than the other ethnic groups. It is possible that fluid and diet restrictions may be particularly difficult for certain patient groups to follow because of cultural norms, therefore leading to poorer medical outcomes. Providing nutritional counseling that is culturally sensitive and working with patients to tailor diets to their specific needs, where possible, may increase their ability to comply. However, in general demographic variables such as race and ethnic background have not proven to be consistently related to adherence among the dialysis population (Bame et al., 1993; Christensen et al., 1997). For example, in two studies of hemodialysis patients, O'Brien (1990) did not find statistically significant associations between race and adherence outcomes, whereas Bame et al. (1993) report that African Americans and Latinos were more compliant with fluid restrictions than White patients. Bame et al. (1993) point out that demographic factors such as race are an efficient way to categorize patients at high risk but do not explain reasons for non-adherence. They call for further research that explores the associated factors that motivate patients to comply with their treatment regiment.

Secondary Practice, Organizational and Research Benefits

Using existing clinical information within an interdisciplinary team approach to explore patient characteristics, social work interventions and outcomes has considerable practice, organizational and research benefits.

- Practice is enhanced as social workers reflectively review their work and gain valuable insights into patients' behavior in relation to dialysis (Ben Shahar et al., 1995). In addition, social workers and other healthcare providers can become more knowledgeable about patients potentially at high risk for negative medical and psychosocial outcomes and tailor their interventions accordingly.
- Chart reviews highlighted areas where documentation was vague or lacking, for example, regarding adherence to the peritoneal dialysis treatment regimen or in relation to some patients' impediments to coping. Certainly, social workers involved in the project had a heightened awareness of the practice benefits, for example, of documenting in the initial assessment problems in coping in order to work with patients towards enhanced outcomes. Furthermore, other renal staff and patients benefit if practice documentation is strengthened.
- For the interdisciplinary team, working together on a creative project away from daily patient care can enhance cohesion among members (Epstein et al., 1997).
- For the social work supervisor, coordinating the project resulted in closer working relationships with renal staff and an invitation to attend biweekly renal management meetings.
- For the social work department, the leadership role of the department in outcomes research relating to patient care constitutes a contribution to a critically important area of research within the Hospital.
- Finally, since End Stage Renal Disease is one of the few mandated areas of social work practice in healthcare, it is fertile ground for research on social work interventions and outcomes.

Although these findings are consistent with a variety of other studies on the dialysis population, they may not be applicable to other renal settings with differing patient populations. However, replication of this study at other sites would result in valuable information about outcomes among other renal populations. Presently, the study is being implemented in Israel and will possibly be replicated with a rural population in the southern United States.

In addition, although there was sufficient information in medical records to make record review a highly feasible methodological strategy, some aspects of patients' experiences were not documented and the lack of documentation could affect the validity of our findings. Finally, although there is potential bias among practitioner-researchers studying their own patients, the secondary benefits to their practice and the efficiency brought to the project far outweighed the possible negative consequences.

CONCLUSION

Providing psychosocial services to dialysis patients involves complex tasks associated with helping patients and families manage an intricate and tedious treatment regimen and dramatic lifestyle changes. It entails an understanding of the impact of renal disease on patients and families and the strengths and problems they bring that affect their ability to manage the illness. It also requires that social workers be able to respond to the need for psychological support and at the same time attend to resource needs. Achievement of balance between the psychosocial and the concrete necessitates a high level of social work knowledge and skill. Equally demanding is the need in many cases to provide help to the patient and family members at the same time, a task which requires understanding of and ability to work with the family as a psychosocial system.

What can be so rewarding for renal social workers–and so challenging–is intervening with patients where the physical, psychological and socioeconomic impact are so intertwined. This study of available clinical information clearly demonstrates the complexity of social work practice with the ESRD population and the critical role of professionally trained social workers in contributing to positive patient outcomes.

REFERENCES

Bame, S.I., Peterson, N., & Wray, N.P. (1993). Variation in hemodialysis patient compliance according to demographic characteristics. *Social Sciences Medicine*, *37*(8), 1035-1043.

Barnard, C.P. (1994). Resiliency: A shift in our perception? *American Journal of Family Therapy*, *22*(2), 135-144.

Ben Shahar, I., Auslander, G., & Cohen, M. (1995). Utilizing data to improve practice in hospital social work: A case study. *Social Work in Health Care*, *20*(3), 99-111.

Boyer, C.B., Friend, R., Chlouverakis, G., & Kaloyanides, G. (1990). Social support and demographic factors influencing compliance of hemodialysis patients. *Journal of Applied Social Psychology*, *20*, 1902-1918.

Brownbridge, G. & Fielding, D.M. (1994). Psychosocial adjustment and adherence to dialysis treatment regimes. *Pediatric Nephrology*, *8*, 744-749.

Burton, H.J., Kline, S.A., Lindsay, R.M., & Heidenheim, P. (1988). The role of support in influencing outcome of end-stage renal disease. *General Hospital Psychiatry*, *10*, 260-266.

Christensen, A.J., Benotsch, E.G., & Smith, T.W. (1997). Determinants of regimen adherence in renal dialysis. In D.S. Gochman (Ed.), *Handbook of health behavior research II: Provider determinants* (231-243). New York: Plenum Press.

Davis, B., Krug, D., Dean, R.S., & Hong, B.A. (1990). MMPI differences for renal, psychiatric, and general medical patients. *Journal of Clinical Psychology*, *46*, 178-184.

Davis, M.C., Tucker, C.M., & Fennel, R.S. (1996). Family Behavior, adaptation, and treatment adherence of pediatric nephrology patients, *Pediatric Nephrology*, *10*, 160-166.

Epstein, I. (1998, January). *Using clinical information in practice-based social work research: Mining for silver while dreaming of gold.* Paper presented at the 2nd International Conference on Social Work in Health and Mental Health, Melbourne, Australia.

Epstein, I., Zilberfein, F., & Snyder, S. (1997). Using available information in practice-based outcomes research: A case study of psychosocial risk factors and liver transplant outcomes. In E.J. Mullen & J.L. Magnabosco (Eds.), *Outcomes measurement in the human services: Cross-cutting issues and methods* (224-233). Washington, D.C.: NASW Press.

Furr, L.A. (1998). Psycho-social aspects of serious renal disease and dialysis: A review of the literature. *Social Work in Health Care*, *27*(3), 97-118.

Gorman, D., & Anderson, J. (1982). Initial shock: Impact of a life-threatening disease and ways to deal with it. *Social Work in Healthcare*, *7*(3), 37-46.

Hener, T., Weisenberg, & Har-Even, D. (1996). Supportive versus cognitive-behavioral intervention programs in achieving adjustment to home peritoneal kidney dialysis. *Journal of Consulting and Clinical Psychology*, *64*(4), 731-741.

Homedes, N. (1991). Do we know how to influence patients' behavior?: Tips to improve patients' adherence. *Family Practice*, *8*(4), 412-423.

Hoover, H. (1989). Compliance in hemodialysis patients: A review of the literature. *Journal of the American Dietetic Association*, *89*(7), 957-959.

Illic, S., Djordjevic, V., & Stefanovic, V. (1996). Psychological status of ESRD patients on hemodialysis. *Dialysis & Transplantation*, *25*(12), 871-880.

Kaplan De-Nour, A.K. & Czaczkes, J.W. (1972). Personality factors in chronic hemodialysis patients causing noncompliance with medical regimen. *Psychosomatic Medicine*, *34*(4), 333-344.

Killingworth, A., & Den Akker, O. (1996). The quality of life of renal dialysis patients: Trying to find the missing measurement. *International Journal of Nursing Studies*, *33*(1), 107-120.

Kimmel, P.L., Peterson, R.A., Weihs, K.L., Simmens, S.J., Alleyne, S., Cruz, I., & Veis, J.H. (1998). Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients. *Kidney International*, *54*, 245-254.

Kimmel, P.L., Weihs, K., & Peterson, R.A. (1993). Survival in hemodialysis patients: The role of depression. *Journal of the American Society of Nephrology*, *4*(1), 12-27.

Kirschenbaum, D.S. (1991). Integration of clinical psychology into hemodialysis programs. In J.J. Sweet, R.H. Rozensky, & S.M. Tovian (Eds.), *Handbook of clinical psychology in medical settings* (pp. 567-586). New York: Plenum Press.

Kutner, N.G., & Brogan, D. (1990). Expectations and psychological needs of elderly dialysis patients. *International Journal of Aging and Human Development*, *31*, 239-249.

Kutner, N.G., & Brogan, D. (1994). Life quality as a function of aging with a chronic illness: Differential assessment by older Blacks and older Whites. *Research in Sociology of Health Care*, *11*, 127-150.

Kutner, N.G., Fair, P.L., & Kutner, M.H. (1985). Assessing depression and anxiety in chronic dialysis patients. *Journal of Psychosomatic Research*, *29*(1), 23-31.

LePard, L.F. (1991). Psychosocial aspects of dialysis in the '90's. *Dialysis & Transplantation*, *20*(10), 600-601.

Leggat, J.E., Orzol, S.M., Hulbert-Shearon, T.E., Golper, T.A., Jones, C.A., Held, P.J., & Port, F.K. (1998). Noncompliance in hemodialysis: Predictors and survival analysis. *American Journal of Kidney Diseases*, *32*(1), 139-145.

Levenson, J.L., & Glocheski, S. (1991). Psychological factors affecting end-stage renal disease: A review. *Psychosomatics*, *32*(4), 382-389.

McCubbin, H.I., McCubbin, M.A., Thompson, A.I., Han, S.Y., & Allen, C.T. (1997). Families under stress: What makes them resilient. *Journal of Family and Consumer Sciences*, *89*, 2-11.

McKevitt, P.M., Jones, J.F., Lane, D.A., & Marion, R.R. (1990). The elderly on dialysis: Some considerations in compliance. *American Journal of Kidney Diseases*, *16*(4), 346-350.

National Kidney Foundation Council of Nephrology Social Workers. (1993). *Renal administrator's handbook on nephrology social work*. New York: National Kidney Foundation.

Nurius, P.S., & Vourlekis, B.S. (1997). Comments and questions for outcomes in measurement in mental health and social work. In E.J. Mullen & J.L. Magnabosco (Eds.), *Outcomes measurement in the human services: Cross-cutting issues and methods* (144-148). Washington, D.C.: NASW Press.

O'Brien, M.E. (1990). Compliance behavior and long-term maintenance dialysis. *American Journal of Kidney Diseases*, *15*(3), 209-214.

Ozminkowski, R.J., White, A.J., Hassol, A., & Murphy, M. (1997). General health of end stage renal disease program beneficiaries. *Health Care Financing Review*, *19*(1), 121-144.

Parboosingh, E.J. & Larsen, D.E. (1987). Factors influencing frequency and appropriateness of utilization of the emergency room by the elderly. *Medical Care*, *25*(12), 1139-1146.

Pierce, J.M., Kellerman, A.L., & Oster, C. (1990). "Bounces": An analysis of short-term return visits to a public hospital emergency department. *Annals of Emergency Medicine*, *19*(7), 752-757.

Streltzer, J. & Hassell, L.H. (1988). Noncompliant hemodialysis patients: A biopsychosocial approach. *General Hospital Psychiatry*, *10*, 255-259.

Vourlekis, B.S., & Rivera-Mizzoni, R.A. (1997). Psychosocial problem assessment and end-stage renal disease patient outcomes. *Advances in Renal Replacement Therapy*, *4*(2), 136-144.

Wolcott, D.L., Nissenson, A.R., & Landsverk, J. (1988). Quality of life in chronic dialysis patients: Factors unrelated to dialysis modality. *General Hospital Psychiatry*, *10*, 267-277.