
Home Hemodialysis and Quality of Life

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Home hemodialysis (HH) has been gaining the attention of renal professionals and patients. Most published studies of HH have been limited in their "generalizability" by small samples and limited descriptive and outcome data. This article describes the HH patients at a moderately sized regional dialysis center and details a measurement of quality of life (QOL). Using the Medical Outcomes Survey short form (SF)-36, baseline scores were compared with 6-month follow-up scores (N = 36). Statistically significant improvement was found in three of the SF-36 domains: role-physical (p = 0.031), vitality (p = 0.018) and social functioning (p = 0.025), as well as physical component summary scores (p = 0.047). There were small nonsignificant improvements in all other domains. The results demonstrate improved QOL for patients using HH.

INTRODUCTION

Home hemodialysis (HH) has recently gained the attention of many dialysis units, the Centers for Medicare and Medicaid Services, nephrologists, renal health professionals and particularly dialysis patients. To date, most published studies of HH have been limited in their generalizability by small samples and limited descriptive and outcome data and have generally served as an inspiration for others to develop similar programs. To address this shortfall, this article describes the patients at a moderately sized regional dialysis center, serving both urban and rural areas and details a measure of outcome: quality of life (QOL).

HH, both quotidian (hemodialysis done 5 to 6 times a week for 2 hours) and nocturnal (hemodialysis done 5 to 6 times a week for over 4 hours, generally at night), provides an opportunity for dialysis patients to have more control over their time with reduced symptoms (Heidenheim et al., 2003). Uremic symptoms include sleep disorders, itching, loss of appetite and difficulty concentrating. These uremic symptoms, fatigue and dietary restrictions that normally compromise the hemodialysis patients' QOL have been shown to decrease significantly after patients switch to short hours daily dialysis (Heidenheim et al., 2003). Studies have suggested that hemodialysis patients' QOL has improved when changing from conventional dialysis to more frequent home treatments (Kjellstrand, 2007). An overall sense of well-being is indicated with benefits of increased energy, strength and endurance. From a social work perspective, this is a most desirable outcome.

Dialysis Center of Lincoln Program

The Dialysis Center of Lincoln (DCL) consists of five dialysis units all located in Nebraska: three in the city of Lincoln (population 225,000), one in Beatrice (population 12,500, located 40 miles from Lincoln) and one in Columbus (population 21,000, located 80 miles from Lincoln). The HH program is based in Lincoln but serves patients from all units. Of the patients in the HH program, 69% come from this geographic service area, 24% from other areas in Nebraska and 7% from other states with no HH programs in their areas, including Iowa, Kansas and California. The patients from the surrounding states are able to drive to their monthly clinic visits. The patient from California has family in Lincoln and flies in for clinic visits. HH and peritoneal

dialysis (PD) patients make up the Home Dialysis Program at DCL. The dialysis team includes seven nephrologists, four nurses, a social worker and a dietitian. The patients are seen in monthly clinics by a health care professional from each of these disciplines.

DCL has been training quotidian home dialysis since September 2003. As of March 1, 2008, 54 patients had completed training to dialyze at home. The present census is 34. The Aksys PHD was the first machine used with 14 patients trained, and was used until it was discontinued in January 2007. The NxStage One has been used since March 2005 and is presently used for all of the patients.

Since the establishment of the HH program at DCL, there have been seven patients who did not complete training; three who were medically unsuited due to comorbid conditions, one who was transferred to a dialysis unit closer to her home, two who preferred in-center hemodialysis and one who lacked adequate support to dialyze at home. Of the 54 who completed the training, 20 left the program. Five have been transplanted, with 1 failure resulting in the patient's return to HH; 10 died, with all deaths related to other medical issues; 4 returned to in-center hemodialysis; and one returned to PD. Those returning to other modalities either found the experience overwhelming, had complicated medical issues or had an assistant who had difficulty. Of the 54 trained HH patients, 30% (9) successfully dialyzed at home without a partner. The remaining 70% (38) had partners, and 13% (7) dialyzed with their partner doing all of the procedures.

Demographics

Nearly half of the 54 patients were between the ages of 45 and 64 (49.1%) and 36% were older than 65 years of age. These data are in agreement with national percentages, which indicate that the largest age group on dialysis is between 45 and 64 (U.S. Renal Data System, 2006). With the large number of patients over 65, it is not surprising that almost 34% of the patients were retired. Slightly more than 15% of the DCL HH population is between 20 and 46 years of age. There were exactly 50% males. Eleven percent of the HH population was non-Caucasian: one Native American, one Hispanic, and four African Americans. Sixty-five percent had more than a high school education.

DCL HH patients can be classified as primarily rural, with almost three times as many patients who lived outside urban settings than those who lived in areas with population exceeding 200,000. HH lends itself to rural settings because it saves transportation time and expense for patients living more than an hour from a dialysis unit. Travel is only necessary for monthly clinic visits and lab draws (if they are not available in the patient's home community).

As with most dialysis populations (U.S. Renal Data System, 2006), our largest primary diagnosis was type II diabetes (28.3%). Type I diabetes (7.5%), hypertension (9.4%) and glomerulonephritis (16.9%) were the other primary diagnoses. Of the 54 patients, 15 were employed part-time (16.98%) or full-time (11.32%). One was a student, 10 were homemakers, 19 (33.96%) were retired and 9 (16.98%) were receiving disability.

QOL

DCL HH patients consistently reported feeling much better than prior to entering the program. Most valued the freedom in scheduling their own dialysis and opportunity to be involved in other activities, such as continuing to work, volunteering and being more involved with their family. Measuring these and other variables as indicative of QOL provides an important assessment of hemodialysis' affect on patients. In addition to patients' medical concerns, their ability to function in daily life and their sense of well-being define the value of delivered care and are essential components in evaluating medical treatment (Kutner, 2004; Rettig et al., 1997; Tandon, 1990). At DCL, the impact of quotidian HH on the patient's perception of their health and QOL is routinely assessed with the Medical Outcomes Survey short form (SF)-36.

The SF-36 has been used to measure the QOL in the renal population since the early 1990s (Kurtin et al., 1992). This self-assessment questionnaire includes a multi-item scale that assesses eight health domains: (1) physical functioning (PF): limitations in physical activities because of health problems; (2) social functioning (SF): limitations in social activities because of physical or emotional problems; (3) role-physical (RP): limitations in usual role activities because of physical health problems; (4) bodily pain (BP); (5) general mental health (MH): psychological distress and well-being; (6) role-emotional (RE): limitations in usual role activities because of emotional problems; (7) vitality (VT): energy and fatigue; and (8) general health (GH) perceptions (Ware & Sherbourne, 1992). Mental health component (MCS) and physical health component (PCS) summary scores are calculated from these domain scores (Ware & Sherbourne, 1992).

The SF-36 has been used to assess QOL in HH patients in only a few studies. Lindsay & Kortas reported no improvement in SF-36 PCS scores for patients on short daily hemodialysis ($N = 20$; 2001). Reynolds et al. found no changes in PCS and MCS scores ($N = 12$; 2004). Heidenheim et al. reported marginal improvement in the PF, RP and BP subscales, as well as RE and MH subscales (2003). In Heidenheim et al.'s study ($N = 23$), there were statistically significant improvements

in the PCS, as well as MCS (2003). Kooistra et al. reported statistically significant improvements in MH and VT done in the Netherlands ($N = 13$; 1998).

Based on observations and anecdotal reports of feeling better, being able to do more and enjoying the ability to control the scheduling of their dialysis; it was hypothesized that the SF-36 scores among DCL's HH patients would increase over time, reflecting an improvement in their QOL in all eight domains, as well as the MCS and PCS scores.

METHODS

SF-36 scores from DCL's 54 HH patients were examined. Baseline measurements were obtained during their training for quotidian HH. Follow-up questionnaires were administered at 6-month intervals. Of the 54 patients, 18 did not complete follow-up questionnaires; 36 completed at least one follow-up SF-36. The mean age of the 36 patients in the analysis was 58.5 with the largest percentage (50%) of patients falling between 45 and 64 years of age. Eighty-nine percent were Caucasian, a reflection of the rural Nebraska population, with one Native American and three African Americans. Almost 42% of this population was retired and 25% were employed. Type II diabetes was the largest diagnosis group (25%). There were slightly more males (52.2%) than females and nearly 64% have received some college education or have graduated from college. More than 66% reside in rural areas, again, a reflection of Nebraska' population. Table 1 illustrates the break down of demographic information.

Table 1

Demographic Composition of Quality-of-Life Study, Dialysis Center of Lincoln, March 2008

N = 36		DEMOGRAPHICS			
	Count	%		Count	%
Age			Education		
0-19	0	0	Grade school	1	2.8
20-44	6	16.7	High school	12	33.3
45-64	18	50	Some college	15	41.7
65-74	9	25	College graduate	8	22.2
75+	3	8.3	Primary Diagnosis		
Race			Type I diabetes	2	5.5
Caucasian	32	89	Type II diabetes	9	25
Native American	1	2.7	Hypertension	4	11.1
Hispanic	0	0	Polycystic	3	8.4
African American	3	8.3	GN/GS	6	16.7
Employment			Lupus	2	5.5
Retired	15	41.7	Other	10	27.8
Disability	7	19.4	Gender		
Part-time	4	11.1	Male	19	52.2
Full-time	5	13.9	Female	17	47.8
Homemaker	5	13.9	Location of Residence		
Student	0	0	Rural	24	66.7
			Urban	12	33.3

Records from these 36 patients are used in this analysis. The patients' baseline scores served as their own controls. All patients consented to completing the SF-36 and the use of their data, unidentified in this analysis. The baseline scores were compared with 6-month follow-up scores using repeated analysis of variance measures. This analysis removed variability due to individual differences and provided a sensitive test for treatment differences. SPSS software was used to run the analysis.

RESULTS

Statistically significant improvement from baseline to 6 months was found in 3 of the 8 SF-36 domains: RP ($p = 0.031$), VT ($p = 0.018$) and SF ($p = 0.025$). Additionally, PCS scores significantly ($p = 0.047$) improved over baseline mean. There were small nonsignificant improvements in all other domains with the smallest increase in the MH domain (Table 2). As hypothesized, the SF-36 scores increased over the 6-month interval, reflecting an improvement in QOL for patients using HH.

Table 2

Results of SF-36, Baseline and Follow-Up Dialysis Center of Lincoln, March 2008

N = 36				
Domain	Baseline Mean \pm SD	Follow-Up Mean \pm SD	Significance $p < 0.05$	Effect Size η^2
GH	38.36 \pm 9.85	41.18 \pm 11.45	0.060	
PF	35.44 \pm 9.85	38.05 \pm 12.38	0.113	
RP	35.51 \pm 10.34	40.08 \pm 12.29	0.031	0.127
BP	42.46 \pm 12.10	44.77 \pm 11.22	0.235	
VT	39.34 \pm 11.07	44.89 \pm 11.12	0.018	0.150
SF	42.29 \pm 10.97	47.28 \pm 11.60	0.025	0.135
MH	48.24 \pm 10.97	48.37 \pm 11.56	0.933	
RE	44.34 \pm 12.66	47.58 \pm 10.92	0.195	
MCS	48.16 \pm 10.93	50.91 \pm 10.69	0.153	
PCS	34.66 \pm 10.93	38.14 \pm 11.94	0.047	0.108

DISCUSSION

The major therapeutic goal for most patients with a chronic illness such as end-stage renal disease is not a cure, but rather an improvement in their functioning and ability to enjoy life to its fullest through the alleviation of physical symptoms and the slowing of illness progression (Welch, 1994). To date, only a modest amount of studies have attempted to measure QOL among HH patients despite the fact that it is quite possibly the most promising renal replacement modality. These data and those from the small number of earlier studies suggest that QOL can be measured and that HH leads to improvements in QOL. The significant improvements in the RP, VT and SF domains indicate that the patients

perceive themselves to have improved vitality, increased ability to take part in social aspects of life and fewer limitations in physical role activities. Additionally, small increases in all other domains and significant improvement in PCS summary indicate an overall improved sense of well-being.

From observation, DCL's HH program can be considered very successful. Patient's demographics show that the modality is suitable for a range of ages, even seniors. Many are able to continue work, be active in family life and participate in the community activities. The number of patients continues to grow. The patients express satisfaction with this modality and report a new sense of enjoyment of life.

The SF-36 scores comparing baseline to follow-up support the belief that there is improvement in the QOL of HH patients. This finding matches their self-reports of feeling better and being able to do more of the things they enjoy. Patients have been able to integrate dialysis into their new definition of normalcy. Although not part of this study, other researchers have reported improvements in fluid management, uremic symptoms and personal empowerment (Heidenheim et al., 2003). Of at least equal importance to the medical-related improvements are the improvements in outlook, hope and senses of control and freedom, as well as strength and endurance. This is of particular interest to social workers as they advocate for the best QOL possible for patients.

The manner in which dialysis patients and their renal failure are approached may allow patients to understand the concept of illness as distinct from disease. Illness perception has been shown to be more closely associated with psychosocial outcome in renal groups than have objective measures of disease severity (Sacks et al., 1990). There may be potential for the alleviation of psychosocial difficulties in renal disease by attention to the manner in which the disease is construed. Social workers, as well as other renal professionals, can promote HH as an independent modality that has been successful with many different patients. The belief that the patients and their family can accomplish hemodialysis at home with improved QOL as demonstrated by this study and other research should translate to patients as hope. Although kidney failure and the introduction of dialysis means disruption and difficult life adjustments, HH provides a sense of control and opportunities to maintain their lives in a manner that allows them to continue to be involved in activities they value.

Although the number of subjects in this study is greater than previous studies, the need continues for more research in this area. With growing HH programs, the dialysis community is coming closer to having conclusive research to support this dialysis modality. Studying QOL measures over a longer period of time and with larger numbers of subjects can only add to the body of knowledge about this growing modality.

REFERENCES

- Heidenheim, P., Muirhead, N., Moist, L., & Lindsay, R. (2003). Patient quality of life on quotidian hemodialysis. *American Journal of Kidney Diseases*, 42(Suppl. 1), S36–S41.
- Kjellstrand, C., & Ting, G. (2007). Daily hemodialysis: Dialysis for the next century. *Advances in Renal Replacement Therapy*, 5, 267–274.
- Kooistra, M. P., Vos, J., Koomans, H. A., & Vos, P. F. (1998). Daily home haemodialysis in The Netherlands: Effects on metabolic control, haemodynamics, and quality of life. *Nephrology Dialysis Transplantation*, 13, 2853–2860.
- Kurtin, P., Davies, A., Meyer, K., DeGiancoma, J., & Kantz, M. (1992). Patient-based health status measure in outpatient dialysis: Early experiences in developing an outcomes assessment program. *Medical Care*, 30(Suppl. 5), MS136–149.
- Kutner, N. (2004). Quality of life and daily hemodialysis. *Seminars in Dialysis*, 17(2), 92–98.
- Lindsay, R. M., & Kortas, C. (2001). Hemeral (daily) hemodialysis. *Advances in Renal Replacement Therapy*, 8(4), 236–249.
- Rettig, R. A., Sadler, J. H., Meyer, K. B., Wasson, J. H., Parkerson, G. R. Jr., Kantz, B., et al. (1997). Assessing health and quality of life outcomes in dialysis: A report on an Institute of Medicine workshop. *American Journal of Kidney Diseases*, 30, 140–155.
- Reynolds, J. T., Homel, P., Canty, L., Evans, E., Harding, P., Gotch, F., et al. (2004). A one year trial of in-center daily hemodialysis with an emphasis on quality of life. *Blood Purification*, 22, 320–328.
- Sacks, C. R., Peterson, R. A., & Kimmel, P. L. (1990). Perception of illness and depression in chronic renal disease. *American Journal of Kidney Diseases*, 15, 31–39.
- Tandon, P. K. (1990). Applications of global statistics in analyzing quality of life data. *Statistics in Medicine*, 9, 819–827.
- U.S. Renal Data System. (2006). *2005 Annual Data Report*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.
- Ware, J., & Sherbourne, C. (1992). The MOS 36-item Short-Form Health Survey (SF36). I: Conceptual framework and item selection. *Medical Care*, 30(6), 473–483.
- Welch, G. (1994). Psychosocial challenges accompanying high technology medicine. In H. McGee & C. Bradley (Eds.), *Quality of life following renal failure* (pp. 55–97). Amsterdam, The Netherlands: Harwood Academic Publishers. 