Health-Related Quality of Life Among Patients Receiving Home Dialysis Therapies

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Little is known about the health-related quality of life (HRQOL) of patients receiving daily home hemodialysis (DHHD) or peritoneal dialysis (PD). The purposes of this study are to describe the HRQOL of these patients and examine the effect of some demographic and illness characteristics on HRQOL. A total of 114 patients from a single Midwestern unit were included. Average physical component summary (PCS) scores were lower than the general population. Both DHHD and PD patients perceived themselves as having good mental health with mental component summary (MCS) scores at or above those of the general population. These results suggest that the control and independence provided by home therapies have a positive effect on patients' outlook on life.

INTRODUCTION

Health-related quality of life (HRQOL) surveys have been used for decades to assess patients with end-stage renal disease. The vast majority of studies conducted with patients receiving in-center hemodialysis (CHD) indicate that these patients have lower physical and mental quality of life (QOL) when compared to the general population, and the physical health dimension is often lower than the psychological dimension (Guerra-Guerrero, Sanhueza-Alvarado, & Caceres-Espina, 2012; Kalantar-Zadeh, Kopple, Block, & Humphreys, 2001). More importantly, lower physical and mental QOL predict hospitalization and death (Lowrie, Curtin, LePain, & Schatell, 2003; Mapes et al., 2003) and are as powerful as serum albumin or dialysis adequacy (DeOreo, 1997; Mapes et al., 2003; Mapes et al., 2004) in predicting adverse events.

Studies from a variety of countries, often over time, have explored the quality of life of patients receiving various types of dialysis. Results have differed for both modes of peritoneal dialysis (PD), continuous ambulatory PD (CAPD) or automated PD using a cycler (APD). Some PD patients showed no major QOL differences between PD modalities over time, though the mental summary score was better for APD than CAPD patients (Michels et al., 2011). Some mental health dimensions were similar to the general population of a study's country (Bro et al., 1999), with no differences over time. However, some CAPD patients had lower physical and mental dimension scores than those of the general population of a study's country (Goller, McMahon, Rutledge, Walker, & Wood, 1997). And still, other studies showed no significant differences for either mental or physical component scales for APD and CAPD patients (Guney et al., 2010). Others reported better mental component scores, similar to those in the general population, with physical function lower than that of the general population. APD and CAPD were essentially equal for HRQOL measures in other studies (de Wit, Merkus, Krediet, & de Charro, 2001; Sunder, Kalra, Nashine, Waghmare, & Ruchi, 2008). Other researchers (Bakewell, Higgins, & Edmunds, 2002; Wu et al., 2004) suggest quality of life for PD patients may be impaired at the start of PD and worsen over time.

Several investigators compared PD patients to CHD patients. While some found no differences between the modalities for quality of life measures (Kim et al., 2013), others noted better functionality for PD patients regarding mental health (Diaz-Buxo, Lowrie, Lew, Zhang, & Lazarus, 2000; Zhang, Cheng, Zhu, Sun, & Wang, 2007). In another study, PD was associated with higher levels of both mental and physical measures (Russo et al., 2010). One recent report on patients in Singapore indicated higher symptoms of depression and poorer physical health, yet higher satisfaction with care with PD compared to CHD (Griva et al., 2014a).

Researchers have reported both reduced dialysis symptoms and improved HRQOL among those receiving short daily home hemodialysis (DHHD) (Heidenheim, Muirhead, Moist, & Lindsay, 2003; Kutner, 2004; Lindsay & Kortas, 2001). A study of one large regional dialysis center also showed improvement in overall quality of life as well as physical component scores for DHHD patients (Buss, 2008). The FREEDOM Study examined the long-term effects of DHHD on HRQOL using a number of assessment tools (Finkelstein et al., 2012) and found that physical and mental component scores improved over time (4 months to 12 months); the increase was less for mental component scores, which were similar to those of the general population. Others comparing frequent in-center (6-day per week) to 3-day per week hemodialysis concluded that more frequent dialysis improved self-reported physical health and functioning (Hall et al., 2012), but did not improve objective physical performance. Home dialysis patients scored higher

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on the physical component of quality of life, compared to CHD patients, though both scored equally well and similar to the general population on the mental component (Watanabe et al., 2014).

A better understanding of the HRQOL of home dialysis patients would assist social workers and other professional staff in developing more effective interventions to help patients improve their HRQOL. The purpose of this study was to describe results on two subscales of the KDQOL™-36: physical (PCS) and mental component scores (MCS), for both DHHD and PD patients from one large home dialysis unit in the Midwestern United States. The PCS and MCS scores were each compared to demographic and illness/disease characteristics. Specific research questions were: 1) What is the HRQOL for patients receiving home therapies (DHHD, PD) and is it different for the two treatments? 2) Does HRQOL differ for individuals receiving DHHD or PD when differentiated by demographic characteristics (age, gender, and race)? 3) Does HRQOL differ for individuals receiving DHHD or PD when differentiated by disease/illness characteristics (diabetes status, length of time on dialysis, access type, adequacy of dialysis (Kt/V), serum albumin, and frequency of hospitalization)?

METHODS

Design, Participants, and Setting

Patients receiving DHHD, CAPD, or APD were included in this retrospective descriptive study. Individuals were ineligible if they had dementia, active psychosis, or cognitive impairment; had not received care from the facility for less than three months; or were non-English speakers/readers for whom there was no native language translation or interpreter (Schatell & Witten, 2012). Patients also were excluded if they were receiving services from hospice, had severe physical disabilities that made them unable to independently complete most major activities of daily living, or had a home hemodialysis thrice-weekly regimen.

Measures

Quality of life.

The Kidney Disease Quality of Life survey (KDQOL-36) was used to measure quality of life. The KDQOL-36 is a derivation of the earlier KDQOL [dialysis version] (Hays, Kallich, Mapes, Coons, & Carter, 1994; RAND Corporation, 2000), and consists of 36 items. In this study, the embedded 12-item SF-12 (Ware, Kosinski, & Keller, 1995) was used as a generic measure of HRQOL to produce both the non-disease-related PCS and MCS scores. The scores are based on t-scores with a mean of 50 and standard deviation of 10 for those in the general population. Higher PCS and MCS scores represent better HRQOL. Validity and reliability have been reported for both the original KDQOL (dialysis version) (Hays et al., 1994) and SF-12 (Lacson, Xu, Lin, Dean, Lazarus, & Hakim, 2010; Ware et al., 1995).

Demographic and illness-related information.

Demographic information included age, gender, and race. Illness-related variables included presence of diabetes, length of time on dialysis, type of access, Kt/V, serum albumin, and frequency of hospitalization during the year. Data were retrieved from the medical record. Length of time on dialysis was calculated from the date of a patient's first training in the modality of use to the date of survey administration. Albumin levels for all patients were recorded on the month the survey was administered or within the month closest to that administration. For all but four DHHD patients, Kt/V values were recorded nearest to or 1 to 2 months prior of the survey administration date. For PD patients, Kt/V values available closest to the survey's most recent administration were recorded. However, the interim ranged from 0 to 8 months, with some labs available only after the survey's administration and others not available at all.

Procedures

The Institutional Review Board reviewed and accepted the study as meeting the criteria for exempt research. Over the course of the calendar year 2012, the KDQOL-36 survey was first administered to new patients about three months after starting dialysis training. For most new patients, the survey was completed after the patient had been home doing his/her own dialysis independently for at least a month. For those experienced and continuing home dialysis patients, the survey was administered annually. The scores used for this study represent those obtained from the patient during the 2012 calendar year.

Patients completed the survey by hand over 10 to 15 minutes, usually during a regularly scheduled monthly clinic visit. For five patients whose native languages were not English and/or whose reading or visual skills were poor, an interpreter, adult family member, or social worker read the questions and answer choices to the patient in his/her native language. Spanish was the primary language for two patients, while Chinese was one patient's only language.

Responses to the survey were entered manually into an online database, the Medical Education Institute's KDQOL-Complete subscription, to allow automatic scoring (Medical Education Institute, 2013). Data entry was double-checked for accuracy.

Data Analysis

The KDQOL-Complete analysis and report subscription program automatically calculates scores for each subscale. Data from the KDQOL-Complete were exported to an Excel spreadsheet. Data on number of months on dialysis modality, Kt/V, serum albumin, and number of hospitalizations during the year were added to the spreadsheet.

Descriptive statistics were used for demographic and illness characteristics of the sample. Data were analyzed by modality (DHHD and PD) and means, medians, and standard deviations of each group were computed and compared. For differences between modality type (DHHD vs. PD), Chi-Square tests were used for categorical variables and Student's t-tests for continuous variables. For associations of MCS and PCS scores with demographic and illness variables, analysis of variance models were used due to variables having more than two categories. All analyses were unadjusted for covariates. All analytic assumptions were verified and all analyses were performed using SAS v9.3 (SAS Institute, 2000-2012)

RESULTS

Study Sample

The KDQOL-36 survey was completed, at least once, by a total of 114 people receiving home dialysis. Fifty-two people were on PD; 62% of these received CAPD. Sixty-two patients were on daily home hemodialysis (DHHD), with 58 on short daily hemodialysis (SDHD) and 4 on extended or nocturnal daily home dialysis (NHHD). Patients ranged in age from 21 to 84 years of age with mean and median ages of 53.6 and 54.5 years, respectively. As shown in Table 1, subjects were predominantly male, equally divided by race, a third with diabetes, and most (69%) on DHHD therapy had fistulas. Mean and median lengths of time on dialysis for all patients were 31.3 and 27.3 months respectively, with a range of 2.5 to 128.9 months. For DHHD, the mean and median were 37.9 and 33.5 respectively with a range of 2.8 to 104.3 months. For PD, the mean and median were 23.4 and 15.8 respectively with a range of 2.5 to 128.9 months. Patients receiving DHHD were significantly more likely to be White ($p = .01$), receiving dialysis for a longer period of time ($p = .03$), not diabetic, and with a higher serum albumin ($p < .01$).

Findings

Overall, mean PCS scores were 39.4 and mean MCS scores were 51.9. As shown in Table 2, there were no significant differences in the PCS or MCS scores by home dialysis modality. Because of this, scores were combined into an overall home dialysis therapy score for the remaining analyses. As shown in Table 3, participants who were younger and non-White had significantly higher PCS scores. There were no significant differences in MCS scores with age, gender, or race. Participants who were diabetic and hospitalized at least once had lower PCS scores. There were no significant differences in MCS scores with presence of diabetes, time on dialysis, dialysis adequacy, or serum albumin.

DISCUSSION

This study provided valuable information about the overall HRQOL of patients receiving home dialysis and the effects of demographic and illness characteristics on their quality of life. The main findings from this study were: 1) there were no significant differences in PCS or MCS by home dialysis modality; 2) PCS scores were better in younger, non-White, non-diabetic patients who remained out of the hospital; and 3) MCS scores were similar to those in the general, non-dialysis population.

Quality of Life Results

Mean SF-12 PCS and MCS scores in the general population have been reported as 50.12 and 50.04, respectively (Ware et al., 1995). Thus, both DHHD and PD patients in this study perceived themselves as more debilitated physically than the general population. In contrast, in another study, patients receiving DHHD had improved physical- and mental-component summary scores over a 12-month period (Finkelstein et al., 2012). In that study, 9% of patients receiving DHHD had a PCS score equivalent to the general population at baseline, increasing to 21% after 12 months of treatment, suggesting more longitudinal data are needed.

Interventions that help patients change their perceptions of their physical capabilities and perceptions about their ability to engage in physical activity and activities of daily living would be helpful. Enhancing physical health and encouraging physical activity (e.g., exercise programs) need to be promoted as well (Painter, 2009). Encouraging improved physical strength, stamina, and energy would be most important for general health, as well as getting back to work.

On average, both DHHD and PD patients perceived themselves as having good mental health with scores at or above those reported decades ago for the general population (Ware et al., 1995). This finding is significant as previous QOL studies have shown that dialysis patients, in general, have lower mental health scores when compared to healthy adults (Guerra-Guerrero et al., 2012). This suggests that the control and independence provided by home therapies may have a positive effect on patients' outlook on life.

Demographic Characteristics and HRQOL

PCS scores were lower in patients who were 40 years of age and older. Other studies have shown that older (≥ 65) patients report better quality of life than younger patients on a HRQOL survey (Brown, 2015; Griva et al., 2014b), though APD results were better than those for CAPD on the KDQOL-SF (Griva et al., 2014b).

More non-Whites had better PCS scores. This is consistent with studies that show that Black hemodialysis patients have better HRQOL scores for the physical components with severe comorbid conditions, though no differences were observed between races for mild to moderate co-morbid conditions (Unruh et al., 2004). It also is contrary to another study that showed Black PD patients with no higher perceived health status and quality of life than White patients (Kutner, Zhang, & Brogan, 2005). Black CHD patients have greater survival than Whites (Feroze et al., 2011). The difference may reflect biologic "hardiness," sociocultural differences, social and spiritual support, or even lower expectations or life experiences that ameliorate negative reactions to dialysis (Kutner et al., 2005). In other words, the results in this study suggest that non-White patients may be more resilient and self-sufficient.

Table 1. Demographic and Illness Characteristics of the Sample

	DHHD (*n* = 62)	PD (*n* = 52)	All (*n* = 114)	*p*-value
Age (years)				ns
20–39	14 (22.6)	9 (17.3)	23 (20.2)	
40–59	26 (41.9)	21 (40.4)	47 (41.2)	
60+	22 (35.5)	22 (42.3)	44 (38.6)	
Gender				ns
Female	24 (38.7)	20 (38.5)	44 (38.6)	
Male	38 (61.3)	32 (61.5)	70 (61.4)	
Race				0.01*
White	42 (67.7)	23 (44.2)	65 (57.0)	
Other	20 (32.3)	29 (55.8)	49 (43.0)	
Diabetes				ns
No	43 (69.4)	32 (61.5)	75 (65.8)	
Yes	19 (30.7)	20 (38.5)	39 (34.2)	
Time on Dialysis (months)				0.03
0–12	13 (21.0)	24 (46.2)	37 (32.5)	
13–36	20 (32.3)	13 (25.0)	33 (29.0)	
37–48	11 (17.7)	8 (15.4)	19 (16.7)	
49+	18 (29.0)	7 (13.5)	25 (21.9)	
Access (DHHD only)				n/a
Fistula	43 (69.4)			
Graft	10 (16.1)			
Catheter	9 (14.5)			
Kt/V				ns
Low (< 1.7 PD or < 2.0 DHHD)	6 (9.7)	9 (20.9)	15 (14.3)	
High (≥ 1.7 PD or ≥ 2.0 DHHD)	56 (90.3)	34 (79.1)	90 (85.7)	
Serum Albumin				< 0.01*
Low (< 3.0g/dL)	3 (4.8)	18 (34.6)	21 (18.4)	
High (≥ 3.0g/dL)	59 (95.2)	34 (65.4)	93 (81.6)	
Hospitalizations				ns
0	34 (54.8)	25 (48.1)	59 (51.8)	
1–2	19 (30.7)	21 (40.4)	40 (35.1)	
3+	9 (14.5)	6 (11.5)	15 (13.2)	

DHHD = daily home hemodialysis; PD = peritoneal dialysis; n/a = not applicable
Values are frequency (percent) for categorical variables and mean (standard deviation); range for continuous variables. *p*-values are from Chi-Square tests for categorical variables and Student's t-test for continuous variables.

Table 2. Physical (PCS) and Mental (MCS) Component Summary Scores by Home Dialysis Modality

	PCS Score	MCS Score
DHHD (*n* = 62)		
Mean (SD)	39.9 (10.7)	52.3 (8.9)
Median	40.2	54.0
Range	15.7–59.8	29.0–64.4
Patients with scores above 50	15 (24.2%)	43 (69.4%)
PD (*n* = 52)		
Mean (SD)	38.7 (10.5)	51.5 (9.7)
Median	40.0	53.2
Range	18.2–54.0	25.7–69.0
Patients with scores above 50	9 (17.3%)	33 (63.5%)
Overall (*N* = 114)		
Mean (SD)	39.4 (10.6)	51.9 (9.2)
Median	40.2	53.9
Range	15.7–59.8	25.7–69.0
Patients with scores above 50	24 (21.1%)	76 (66.7%)
p	ns	ns

DHHD = daily home hemodialysis; PD = peritoneal dialysis
PCS = physical component summary; MCS = mental component summary

Table 3. Physical (PCS) and Mental (MCS) Component Summary Scores by Demographic and Disease/Illness Characteristics

	PCS Scores Mean (SD)	*p*	MCS Scores Mean (SD)	*p*
Age (years)				
20–39	45.37 (9.40)	0.01	52.24 (8.09)	ns
40–59	37.56 (9.86)		52.34 (8.78)	
60+	38.18 (10.94)		51.33 (10.32)	
Gender				
Female	39.75 (10.72)	ns	50.74 (10.36)	ns
Male	39.14 (10.54)		52.68 (8.41)	
Race				
White	37.50 (10.70)	0.03	52.29 (8.48)	ns
Other	41.86 (9.94)		51.46 (10.18)	
Diabetes				
No	41.35 (10.47)	0.01	52.87 (8.06)	ns
Yes	35.58 (9.80)		50.12 (11.00)	
Time on Dialysis (months)				
0–12	37.00 (10.46)	ns	52.69 (9.50)	ns
13–36	40.72 (9.80)		52.00 (8.49)	
37–48	36.49 (9.38)		51.80 (9.17)	
49+	43.30 (11.56)		50.81 (10.15)	
Kt/V				
Low (< 1.7 PD or < 2.0 HHD)	38.68 (11.25)	ns	51.13 (9.76)	ns
High (≥ 1.7 PD or ≥ 2.0 HHD)	39.84 (10.59)		52.00 (8.84)	
Serum Albumin				
Low (< 3.0g/dL)	37.62 (11.86)	ns	50.77 (10.18)	ns
High (≥ 3.0g/dL)	39.77 (10.28)		52.19 (9.02)	
Hospitalization				
0	42.95 (9.73)	≤0.01	52.00 (8.51)	ns
1–2	37.31 (10.57)		52.86 (10.14)	
3+	30.81 (7.23)		49.18 (9.42)	

p-values are from one-way ANOVA models.

Illness Characteristics and HRQOL

It was not unexpected that patients who were diabetic had lower PCS scores because diabetics often have neuropathy in their hands and/or feet, and can be limited in their activities. In this study, PCS scores were also lower in patients with repeated hospitalizations. The finding is consistent with previous findings suggesting lower PCS scores were predictive of higher risks of hospitalization (Lacson et al., 2010).

LIMITATIONS OF THE STUDY AND FUTURE RESEARCH

This was a single unit retrospective study that assessed only 2 of 5 subscales of the KDQOL-36 at one point in time. The characteristics of the sample may limit generalizability of the findings because there were slightly more non-Whites on PD and twice as many Whites on DHHD. In addition, patients on DHHD had been on dialysis longer than those receiving PD. These trends may reflect cultural or economic issues.

Many demographic, disease, and psychosocial issues were not explored: employment, financial status and stresses, etiology of kidney disease, mental health issues, family dynamics, role of the dialysis partner, kidney transplant history, or previous history of dialysis modality. Patients on dialysis, in general, may think of themselves as being “sick” and debilitated, although they engage in normal activities of daily living. Those not working and those receiving disability also may differ from those who continue to work in perceptions of their physical capabilities. It may be that these dialysis patients perceive themselves as not having the physical stamina to work either full- or part-time.

These additional demographic and psychosocial issues would be useful to explore more explicitly in future studies. In addition, future research needs to look at the other subscale scores, scores over time, and the variety of psychosocial characteristics. Finally, there are some data that suggest that anxiety, depression, and lack of ability to identify one’s own emotions are important determinants of HRQOL (Varela, Vazquez, Bolanos, & Alonso, 2011) and may need to be explored more fully in patients on home therapies.

CONCLUSIONS

Administering the HRQOL survey is required of renal social workers. Given the differences in dialysis modalities, one might expect HRQOL to differ. However, few data have been available on home therapies or how they compare. The overall goal of this study was to describe HRQOL for both DHHD and PD and compare them on selected demographic and illness characteristics. While there were limitations to the study, these results suggest that, for both modalities, control and independence as well as flexibility and autonomy may have a positive effect on patient outlook on life, despite perceptions of being more debilitated physically. These findings suggest the need for more HRQOL research among people receiving home therapies.

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