

Quality of Life and Burden of Care of Family Caregivers of Filipino Patients on Hemodialysis and Peritoneal Dialysis

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Introduction

Caregivers play a pivotal role in the management of chronic kidney disease patients such as in medication administration, preparation of special diets, personal care, transportation, and emotional support. Caregivers in the Philippines tend to be family members, most of whom have no experience in caring for sick patients. The responsibilities can become burdensome and may lead to emotional distress which may affect their quality of life.

In recent years, there has been an increasing global epidemic of end stage renal disease (ESRD) requiring dialysis. The onset of ESRD and subsequent recommendation of dialysis as a treatment option involves a change in lifestyle for both patients and their caregivers. Dialysis as a medical intervention increases physical, mental, financial, and social demands. The effects of undergoing dialysis have been studied in patients, however, the impact on their caregivers is less discussed.

This study therefore aims to comparatively assess the quality of life and burden of care of family caregivers of Filipino patients on hemodialysis and peritoneal dialysis.

Methodology

This is an observational, cross-sectional, single center study carried out from August 1 to October 30, 2022 in a tertiary referral center in the Philippines. Eligible participants included family caregivers of patients who have been on hemodialysis or peritoneal dialysis for at least 3 months, aged 18 years old and above and currently enrolled at the outpatient peritoneal or hemodialysis clinics of the center. Respondents were recruited through convenience sampling.

The Zarit Burden Interview (ZBI-22) questionnaire was used to measure the level of subjective burden among family caregivers. It consists of 22 items using a Likert scale ranging from 0 (never) to 4 (always). A unique burden index was obtained with a score ranging from 0 to 88 points. Total scores were interpreted as follows: 0 to 21 little or no burden, 22 to 46 mild to moderate burden, 47 to 55 moderate to severe burden, and 56 to 88 severe burden.

The Abbreviated WHO Quality of Life (WHOQOL-BREF) questionnaire was used to measure quality of life. This contains 26 items and addresses 4 QOL domains: physical health (7 items), psychological health (6 items), social relationships (3 items) and environment (8 items). The mean score of items within each domain was used to calculate the domain score.

Descriptive statistics was used to summarize the general and clinical characteristics of the participants. Frequency and proportion were used for categorical variables (nominal/ordinal), mean and standard deviation for normally distributed interval/ratio variables, and median and range for non-normally distributed interval/ratio variables. Quality of life scores and burden scores were compared between family caregivers of patients on hemodialysis and peritoneal dialysis. Correlation between quality of life scores and burden scores were also explored in each dialysis modality. Mean comparison of quality of life and burden scores were computed via Mann-Whitney U-test. Association between categorical variables were tested using chi-square or Fisher-exact test. Correlation analysis between continuous variables was done using Spearman rho coefficient. All valid data was included in the analysis. Missing data was neither replaced nor estimated. Null hypothesis was rejected at 0.05 α -level of significance. R program was used for analysis.

Results

We included a total of 186 respondents and family caregivers of those undergoing HD or PD were equally represented (n=93 each). Between these two groups, statistically significant differences were noted in terms of marital status, relationship to patient, highest educational attainment, and years relative was on dialysis. Overall, the median age was 43 years old, youngest was 18 and oldest was 69 years old, more than half were female (73.12%), 80% had no known illness at time of survey, and 68% were unemployed. In terms of relationship to the patient, most were spouses or common-law partners (33%), children (29.67%), and parents (18.28%). In addition, 48.92% of participants were college graduates.

Based on the WHOQOL-BREF domain scores (Table 1), only the environment domain which includes financial resources, physical safety and security, home environment, opportunities for acquiring information and skills, physical environment, and transport, showed statistical difference between the two groups, with those in the PD group having a higher median score (56 vs 50, p=.007). On the other hand, the two groups generally had high quality of life scores in the other domains.

Table 1. WHOQOL-BREF domain scores and ZBI-22

WHOQOL-BREF	Overall (n=186)	HD (n=93)	PD (n=93)	p-value
	Median (Range)	Median (Range)	Median (Range)	
Physical health	62.50 (21-89)	58 (21-86)	64 (21-89)	.608s
Psychological	67 (29-96)	63 (33-83)	67 (29-96)	.162s
Social relationships	71 (17-100)	75 (17-100)	67 (17-100)	.801s
Environment	56 (22-94)	50 (22-75)	56 (22-94)	.007s
ZBI-22				
Burden of care	33 (0-60)	39 (5-60)	23 (0-60)	<.001s
Little to no burden	71 (76.34%)	28 (30.11%)	43 (46.24%)	0.04†
Mild to moderate	83 (89.25%)	43 (46.24%)	40 (43.01%)	
Moderate to severe	26 (27.96%)	17 (18.28%)	9 (9.68%)	
Severe	6 (6.45%)	5 (5.38%)	1 (1.08%)	

Statistical tests used: †-Mann-Whitney U test; †-Chi-square test
ZBI-22 Score interpretation: little to no burden (<21), mild to moderate (22-46), moderate to severe (47-55), and severe (≥56 points) burden of care

With the ZBI-22 (Table 1), burden of care showed a significant difference, with those in the HD group having a higher median score (39 vs 23, p<.001). Most respondents in the HD group had mild to moderate burden (46.24%) while in the PD group, majority had little to no burden (46.24%). An important observation was most respondents for both groups feel stressed when they are expected to take care of their relatives while fulfilling their responsibilities for their families and work. Although they also believe that they could be better caregivers to their relatives. High burden was also shown in terms of finances. Respondents for both groups often feel that they do not have enough money to take care of their relatives and also their personal needs.

Table 2. Correlations among subdomains WHOQOL-BREF and Burden of Care

	Correlation coefficient	Interpretation	p-value
Hemodialysis			
Physical health and burden of care	0.0796	Very weak, direct	.448
Psychological and burden of care	-0.0983	Very weak, indirect	.349
Social relationships and burden of care	-0.0862	Very weak, indirect	.412
Environment and burden of care	-0.1304	Very weak, indirect	.213
Peritoneal dialysis			
Physical health and burden of care	0.0408	Very weak, direct	.698
Psychological and burden of care	0.1258	Very weak, direct	.230
Social relationships and burden of care	0.0665	Very weak, direct	.526
Environment and burden of care	0.2530	Weak, direct	.014

Interpretation of correlation coefficients: (+) - direct, (-) - indirect; 0 - no correlation; (0-0.2) - very weak, (0.2-0.4) - weak, (0.4-0.6) - moderate, (0.6-0.8) - strong, (0.8-1.0) - very strong, 1.0 - perfect.

Table 2 presents the correlations among the subdomains of WHOQOL-BREF and burden of care measured by ZBI-22. Only the correlation between environment and burden of care from relatives of patients undergoing peritoneal dialysis showed a weak correlation (p-value= 0.14). The rest of the subdomains showed a very weak correlation with burden of care. Linear regressions on burden of care, age, gender, and years relative was either on hemodialysis or peritoneal dialysis showed no associations with one another.

Conclusion

Family caregivers of Filipino patients on hemodialysis and peritoneal dialysis generally had generally high and comparable quality of life scores except in the environment domain where family caregivers of patients on peritoneal dialysis had better scores. However, caregivers of hemodialysis patients had greater burden of care. Weak correlation was found between environment and burden of care from relatives of PD patients.