

## Original Article

## Caregiver Burden among Peritoneal Dialysis and Hemodialysis Family in Saudi Arabia

Jamal S Al Wakeel<sup>1</sup>, Magda M Bayoumi<sup>2</sup>

<sup>1</sup>Nephrology Division, Department of Medicine, College of Medicine, King Saud University, Riyadh, Saud Arabia

<sup>2</sup>Medical Surgical Nursing, Nursing College, King Khalid University, Mahail, Saudi Arabia

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### ABSTRACT

**Objectives:** Dialysis patients often depend on family caregivers to assist them with their daily life activities and medical needs. Since few studies were conducted, we compare the quantitative burden on family caregiver between hemodialysis (HD) and peritoneal dialysis (PD) in Saudi population.

**Design:** This cross-sectional study was performed by applying Zarit Caregiver burden interview (ZBI)

**Subject:** Fifty HD and 55 PD Saudi caregivers (from July 2010 till July 2011)

**Setting:** King Saud University affiliation hospital, Riyadh, Saudi Arabia

**Results:** In both dialysis therapies, the caregivers were mostly female comprising 35 (70%) HD and 43 (78.2%) PD with  $p = 0.338$ . Mean caregivers' age in HD was 40.6 (11.0)

while PD was 37.5 (9.1) years with  $p = 0.178$ . The total burden in caregivers of PD group was 49.9 (24.5) which is higher than HD group 43.3 (21.7), with  $p = 0.15$ . The caregiver burden score is highly significant with patients' age in both dialysis ( $p < 0.01$ ) but negatively correlated with patients' level of education ( $p = 0.05$ ) in hemodialysis only. The caregiver burden score showed high correlation with caregiver education ( $p < 0.01$ ) and age in hemodialysis only ( $p < 0.01$ ).

**Conclusion:** The caregiver burden among PD and HD family ranked from moderate to severe burden. The correlation between caregivers' burden scores and caregivers' education, caregivers' age and patients' education are negatively correlated only in HD. However, the correlation between caregivers' burden scores and patients' age are significant in both HD and PD.

KEY WORDS: burden, caregiver, dialysis, King Saud University, Saudi

### INTRODUCTION

End stage renal failure is usually treated by transplantation, central or hospital hemodialysis and home peritoneal dialysis. Hemodialysis is usually performed in three sessions per week and each session is usually conducted for four hours. Peritoneal dialysis is usually done at home manually by exchanging the fluids every six hours, or at night using peritoneal dialysis machine for dialysis for nine hours.

Dialysis patients often depend on family caregivers to assist them in their daily life activities and medical needs. However, the duties included driving to dialysis center, maintenance of personal hygiene, medical administration, following special diet instructions,

other medical inquiries and appointments. Caregivers usually experience physical and psychological distress as well as limitations to their personal, social activities, and financial burden<sup>[1, 2]</sup>. Additionally, patients' circumstances can have strong impact in the caregivers<sup>[3, 4]</sup>. The numbers of dialysis patients worldwide is constantly growing which has been detailed in the 2011 annual report of the Saudi Center for Organ Transplantation (SCOT). From 13,356 of total dialysis patients, 12,116 were reported as hemodialysis patients and 1,240 as peritoneal dialysis patients<sup>[5]</sup>.

To determine the burden in the caregiver of patients with chronic illnesses, Zarit Caregiver burden interview (ZBI) was performed in various studies<sup>[6, 7]</sup>.

#### Address correspondence to:

Professor Jamal Saleh Al Wakeel, Professor of Internal Medicine and Consultant Nephrologist, King Saud University, Department of Medicine – (38), P.O. Box 2925, Riyadh, 11461, Saudi Arabia. Tel: 00966 11 4671531; Fax: 00966 11 4672671; Email: jwakeel@ksu.edu.sa

In addition, it was also conducted to assess the burden in hemodialysis and peritoneal dialysis caregiver<sup>[8-16]</sup> which showed caregiver burden range from mild to moderate score<sup>[8,9]</sup>.

Few studies were conducted by comparing caregivers' burden in hemodialysis and peritoneal dialysis. This indicates a worst outcome in peritoneal dialysis caregivers<sup>[8-13]</sup>. In this study, our aim is to compare the quantitative burden of family caregivers in HD and PD patients in Saudi Arabian population using Zarit Caregiver burden interview (ZBI) and to analyze the factors associated with this score.

## MATERIALS AND METHODS

This is a cross-sectional, descriptive study conducted in affiliation with King Saud University, Riyadh, Saudi Arabia from July 2010 – 2011 comprising all consented primary family caregivers who were considered as members of the family mainly responsible for looking after the hemodialysis and peritoneal dialysis patients and most closely responsible in his/her care. The inclusion criteria were caregivers with age >18 years, caregivers for hemodialysis patients who had three sessions per week and home peritoneal dialysis caregivers who performed three or more fluid exchanges per day. An interview was conducted by the co-investigator to the caregivers through personal or phone interview.

The only exclusion criterion was the caregivers who were caring patients with stroke or dementia.

Caregivers' backgrounds are comprised of age, sex, work status, marital status, level of education, and health problems. Other burdens of the caregivers are related to their financial burdens and any additional family member of the patient taken care by the caregiver.

**Caregiver Burden Interview:** Subjective Caregiver Burden was calculated using Zarit Caregiver Burden Interview (ZBI) which was developed by Zarit in 1985<sup>[6,7]</sup>. This scale categorized the Burden Interview through factor analysis that yielded two factors that represent the dimensions of personal strain and role strain. The instrument was translated into Arabic language<sup>[7]</sup>. It was tested and validated by Bachner Y<sup>[7]</sup>.

**Scoring:** The level of subjective burden was determined accordingly from little to no burden which ranges from 0 - 20, then 21 - 40 for mild to moderate, then 41 to 60 for moderate to severe and 61 - 88 for severe burden. This study was approved by Institutional Review Board in King Saud University for its completion.

**Statistical analysis:** The SPSS v 18.0 statistical software package was used for statistical analysis. ANOVA variance test and Pearson correlation was

Table 1: Comparison of hemodialysis and peritoneal dialysis patients' personal characteristics in the two study groups

Patient characteristics	Group				Chi-Square Test	p-value
	Hemodialysis (N = 50)		Peritoneal dialysis (N = 55)			
	No.	%	No.	%		
Age (years)						
<40	15	30.0	9	16.4		
40 - 60	28	56.0	17	30.9		
>60	7	14.0	29	52.7	17.43	
Range						
Mean (SD)	46.6 (14.0)		56.2 (13.9)			<0.001*
Gender						
Male/Female	23/27	46/54	22/33	40/60	0.39	0.535
Dialysis duration (months):						
<24	4	8.0	19	34.5		
24 - 60	22	44.0	34	61.8		
>60	24	48.0	2	3.6	30.80	
Range						
Mean (SD)	75.1 (62.8)		26.5 (12.0)			<0.001*
Caregiver						
Spouse/children	36	72.0	45	81.8		
Others	14	28.0	10	18.2	1.43	0.231
Education						
Illiterate	9	18.0	31	56.4		
Basic/intermediate	32	64.0	24	43.6		
High Education	9	18.0	0	0.0	22.06	<0.001*
Marital status						
Married/Unmarried	30/20	60/40	47/8	85.5/14.5	8.68	0.003*

(\*) Statistically significant at p <0.05



**Table 2:** Comparison of caregivers' personal characteristics in the two study groups

Patient characteristics	Group				Chi-Square Test	p-value
	Hemodialysis (n = 50)		Peritoneal dialysis (n = 55)			
	No.	%	No.	%		
Age (years)						
<30	10	20.0	9	16.4		
30 - 40	14	28.0	25	45.5		
>40	26	52.0	21	38.2		
Range						
Mean (SD)	40.6 (11.0)		37.5 (9.1)		3.46	0.178
Gender						
Male	15	30.0	12	21.8		
Female	35	70.0	43	78.2	0.92	0.338
Relation to patient						
Spouse/children	31	62.0	44	80.0		
Others	19	38.0	11	20.0	4.16	0.041*
Education						
Illiterate	10	20.0	20	36.4		
Basic/intermediate	22	44.0	35	63.6		
High	18	36.0	0	0.0	24.12	<0.001*
Marital status						
Married	39	78.0	34	61.8		
Unmarried	11	22.0	21	38.2	3.24	0.072
Have children						
No	8	16.0	14	25.5		
Yes	42	84.0	41	74.5	1.41	0.234
Job						
Unemployed/housewife	30	60.0	38	69.1		
Working	20	40.0	17	30.9	0.95	0.33
Have health problems						
No	18	36.0	23	41.8		
Yes	32	64.0	32	58.2	1.39	0.499

(\*) Statistically significant at  $p < 0.05$ 

used for the analysis and collection of quantitative variables. Multiple stepwise backward regression analysis was used, and analysis of variance for the full regression models was done. Statistical significance was considered at  $p$ -value  $< 0.05$ .

## RESULTS

The socio-demographic characteristics of 50 hemodialysis and 55 peritoneal dialysis patients are shown in (Table 1). As observed, both sexes represented nearly similar frequencies in the study sample. Patients' mean age in hemodialysis were 46.6 (14.0) year and in peritoneal dialysis 56.2 (13.9) year with  $p = 0.001$ . The mean hemodialysis duration was 75.1 (62.8) months compared to 26.5 (12.0) in peritoneal dialysis patients with  $p < 0.001$ . Hemodialysis patients had a higher educational attainment while the percentage of illiteracy in peritoneal dialysis patients was 56.4%. Our data also showed that 40.0% of hemodialysis patients were unmarried and 85.5% of peritoneal dialysis patients were married ( $p = 0.003$ ).

The personal characteristics of caregivers in hemodialysis and peritoneal dialysis are shown in (Table 2). In both dialysis therapies, caregivers were

mostly female, unemployed and married housewife. Half of the caregivers were reported to have health problems.

In our study, we present the comparison in hemodialysis ( $n = 50$ ) and peritoneal dialysis ( $n = 55$ ) caregiver burden score in role, personal and total domain which we illustrate in mean  $\pm$  standard deviation. The role domain in caregiver burden score for hemodialysis group was  $50.0 \pm 25.4$  versus  $50.2 \pm 26.2$  for peritoneal dialysis which shows no significance ( $p = 0.973$ ). The personal range in hemodialysis contains  $39.5 \pm 19.7$  versus  $48.5 \pm 23.7$  for peritoneal dialysis which shows significant high burden score ( $p = 0.039$ ). However, the total domain for hemodialysis was  $43.3 \pm 21.7$  and  $49.9 \pm 24.5$  in peritoneal dialysis which means no significance in caregiver burden score ( $p = 0.15$ ).

Regarding the correlation coefficients between caregivers' burden scores and their age, education, and patient's duration of illness using Pearson correlation coefficients, it shows in hemodialysis group, there are statistically significant moderate negative correlation between caregivers' age and the total score ( $r = -0.444$ ,  $p < 0.01$ ), role strain ( $r = -0.386$ ,  $p < 0.01$ ), and personal strain ( $r = -0.458$ ,  $p < 0.01$ ). Moreover, using



the Spearman rank correlation, we found significant correlation between caregivers' level of education and the total score ( $r = -0.416$ ,  $p = <0.01$ ), role strain ( $r = -0.334$ ,  $p <0.05$ ), and personal strain ( $r = -0.458$ ,  $p <0.05$ ). Conversely, in peritoneal dialysis group, we found that there are no statistically significant correlation between caregivers' burden scores (role, personal and total) and age, duration and level of education ( $p >0.05$ ). We also obtained correlation values for age ( $r = 0.256$ ,  $p >0.05$ ), duration ( $r = -0.077$ ,  $p >0.05$ ) and education ( $r = 0.144$ ,  $p >0.05$ ) in role domain. Respectively, the correlation values for age was  $r = 0.129$ ,  $p >0.05$ ; for duration,  $r = -0.009$ ,  $p >0.05$  and for education,  $r = 0.226$ ,  $p >0.05$  for personal domain. Consequently, the correlation values were  $r = 0.175$ ,  $p >0.05$  for age;  $r = -0.035$ ,  $p >0.05$  for duration and  $r = 0.146$ ,  $p >0.05$  for total domain.

## DISCUSSION

Family caregivers experienced a relationship burden based on role strains and unhealthy feeling such as grief, loss, sadness, anger, frustration, shame, and guilt resulting from taking care of patients with chronic diseases at home [2, 3].

Strain and burden, if left untreated, can result to poor physical and mental well being of the family caregivers [14, 15]. For these reasons, our study intended to investigate and differentiate the burden of family caregivers in both hemodialysis and peritoneal dialysis patients. However, some literatures provide conflicting views regarding the caregivers' characteristic and score of burden. In our study, we reported that the total caregiver burden enrolled in peritoneal dialysis group 49.9 (24.5) was higher than caregivers in hemodialysis group 43.3 (21.7). However, this data appeared to be not statistically significant, since it scored from moderate to severe burden in both dialyses. We also showed the correlation between caregiver burden score and the age of patients in both hemodialysis and peritoneal dialysis. Nevertheless, the caregiver burden score showed a negative correlation with patient level of education, caregiver level of education and caregiver age in hemodialysis group. Our study differs with Saksako Shomoyamo [16] from Japan which showed that the mean caregiver burden calculated by the use of ZBI was 14.1, which is considered as low. This difference can be related to a younger age in peritoneal dialysis in Japan since their mean age was 48.2 years while the mean age of our patient was 56.2 years, whereas more than 83.6% of our patients were >40 years old and 52.7% more than 60 years. In addition, the mean age of caregivers in Japan were 46.4 years compared to our younger caregivers, where the mean age was 37.5 (9.1) years.

Our study agrees with the study of Avsar U [17] *et al*, in which they compared the caregiver burden to patient caregivers in peritoneal dialysis and to transplanted group which showed that more than 68% of caregivers in peritoneal dialysis had moderate to severe scores which indicates that CAPD caregivers had 2.61 times (95% confidence interval, 1.03 - 6.59;  $p = 0.043$ ) greater burden than those in transplanted group.

Belasco *et al* [12] studied the quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis; and found that most caregivers of the elderly aged 55 (15) years were women (78%), sons or daughters of the patients (41%) and 50% of the patients were wives or husbands. These results are in accordance with the findings of the present study, that the mean age of the caregivers' of HD patients are older than caregivers' of the PD group and the total burden was higher in the caregivers' of PD patients than caregivers' of the HD patients.

We also found out that the effect of educational level may decrease the burden of hemodialysis caregivers [10]. However, Suri *et al* [1] reported that more than one-quarter of 236 unpaid caregiver participants in hemodialysis patients had extremely high perceptions of burden and were not associated among perceived caregiver burden with demographic factors such as age, sex, race and level of education [1]. Our findings showed that the caregivers' level of education is statistically significant and was a negative predictor to the total burden of caregivers in HD group, but not in PD, since most of our PD patients and caregivers were illiterates or had only basic or intermediate education.

Since PD is a home dialysis, it should be compared with home hemodialysis, as Mollaoğlu M [11] showed that the mean ZBI score in caregiver of home hemodialysis patient was moderate to severe 52.1 (8.6%) which has the same score with our PD caregivers (49.9, 24.5%). However, his study showed that the mean score of ZBI was significantly high in young caregivers and with high educational level. However, we had a contrasting result since our study found that the total burden scores were negatively significant in hemodialysis patients, but not in peritoneal dialysis. This can be explained as our hemodialysis patients were under hospital care and not at home.

Despite the growing recognition of the burden and adverse effects of CKD in informal caregivers, very little evidence is available about the effect of information or support interventions on their physical or psychosocial well-being. The lack of evidence may be due to inadequate advocacy, funding and support resources available to develop, implement and evaluate the support and information interventions for informal caregivers.



### Limitations

The limitation of this study is that it consisted of a small sample size and that the study was done in single tertiary dialysis hospitals which do not represent the whole population of dialysis caregivers in Saudi Arabia.

### CONCLUSION

In conclusion, this study highlights the value of subjective burden in family caregivers of dialysis patients who had variable degrees of burden between both groups. Our study reported that the caregiver burden among PD and HD family ranked from moderate to severe levels. The burden increased in hemodialysis caregivers with the increase in age of the caregiver and patient as well as with the decrease in the level of education of hemodialysis patients and caregivers.

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