

The Burden for Caring Patients on Maintenance Hemodialysis is Influenced by Social and Demographic Factors

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Abstract

Caregiving by family members is an invaluable and essential support for chronic ill patients. However, physical and psychological stress associated with long-term caregiving may also affect the well-being and life quality of caregivers. Herein we assessed the burden for caring patients on maintenance hemodialysis by primary family caregivers. 151 patients and their 151 primary family caregivers were recruited. Patients were on hemodialysis for an average of 3.56 years. Self-perceived Zarit Caregiver Burden Scale and WHO-5 well-being index were measured in caregivers. Caregiving related physical and emotional distress was present in 115 out of 151 caregivers. Social and demographic factors including age, educational levels, caring hours and relationship with patients were correlated with the severity of burden. Additionally, caring for patients with diabetes, multiple comorbidities, lower income and higher medical expense increased the burden for caregivers. In conclusion, our study demonstrated that caregiver burden was commonly present in family caregivers of patients on maintenance hemodialysis. Several social and demographic factors in caregivers and patients contributed to caregiver burden.

Keywords: Caregiver burden; Hemodialysis; End stage renal disease

Introduction

Maintenance hemodialysis is the mostly applied renal replacement therapy for patients with end-stage renal disease. Although hemodialysis has become a highly safe medical procedure that significantly extended life of uremic patients, [1-3] it is nevertheless a stressful and lengthy treatment process with few but ever-present minor to severe adverse events such as equipment or facility failures, vascular access dysfunction, needle disconnection and infiltration, blood pressure abnormalities, and dialysis circuit or blood line clotting. Moreover, hemodialysis is usually performed at clinic or hospital where patients are required to attend for a four-hour treatment session three times per week [4]. Since uremic patients are commonly comorbid with various diseases, i.e., frailty, hypertension, diabetes, cardiovascular disease, infection, and mineral and bone disease, maintenance hemodialysis remains problematic and physically and psychologically challenging to patients [5]. Therefore, it is essential to provide consistently both medical and personal life cares for hemodialysis patients.

In China, end-stage renal disease is still considered as a fatal disease to the most of patients and the task of personal life care for patients in maintenance hemodialysis falls primarily on one of the core family members, i.e., spouses, parents, adult-children, siblings, and daughter- or son-in-laws. The caregiver is expected to aid in patient's daily life and most of medical activities in between the dialysis [6-8]. When patient becomes more ill or has acute event, new disease(s) and complication(s), caregiver's workloads and responsibilities are overwhelmed, resulting in increased physical, emotional and financial burden and stress [9-11]. Survey on caregivers for hemodialysis

patients from other ethnics and countries have revealed the presence of significant physical and psychological stress and burden that affect the quality of life and mental and physical health of caregivers [12-14]. Since traditional Chinese culture would not allow the family caregiver to have an open complain, this may further add the stress levels and psychological burden. In this study, we examined the burden of caregivers from a single Chinese hemodialysis center and explored the factor(s) that affected the burden.

Subjects and Methods

This survey was conducted on family caregivers of 151 patients at hemodialysis center of the Second Hospital, Dalian Medical University between January and June 2016 (Figure 1). Informed consent was obtained from each patient before the study. Their main caregivers who were over 18 year-old without hearing difficulty or mental disease and agreed to participate were recruited. Both patients and their caregivers were informed that they had right to withdraw from the study at any time without reason.



Figure 1: Dialysis center at Second Hospital.

The Zarit Caregiver Burden Scale (ZCBS) is a self-measured 22-item questionnaire with a five-item response set ranging from "never" to "nearly always", a score of 0 to 20 points meaning little or no burden,

21-40 points meaning mild to moderate burden, 41-60 points meaning moderate to severe burden, and above 61 points meaning severe burden [15]. ZCBS has been used extensively to assess caregiver burden in various chronic diseases and ethnicities and has also been adapted to Chinese with high reliability and validity. Thus, we also applied ZCBS to determine the caregiver burden for hemodialysis patients. The World Health Organization Five-item Well-Being Index (WHO-5) was assessed at the same time with a score ranging from 0 to 25, 0 indicating worst possible and 25 indicating best possible quality of life. A score below 13 or an answer of 0-1 in any of 5 items would be tested for major depression under the International Classification of Diseases. WHO-5 has shown sufficient validity for depression screening and has been applied successfully without modification in Chinese [16,17]. All questionnaires were filled in privately by each caregiver and an independent investigator who has a national certificate as a psychological counsellor was assigned to give instructions and provide assistance on questionnaire related issue(s) raised by caregivers.

Statistical analysis

Continuous variables were expressed as mean ± SD. Categorical variables were expressed as number. Since there were uneven distributions of Zarit scores in our caregivers, Log 2 transformation in all values were performed and normal distributions were achieved after the correction. The differences among the variables were analyzed using the independent samples t tests and one-way ANOVA. The Linear Relationship Between two quantitative variables was determined by Pearson **correlation analysis**. A significance level of 0.05 was used for all tests. All statistical analyses were performed using SPSS19.0 software.

Results

Demographic characteristics of patients and caregivers

Among 151 patients, there were 64 females and 87 males. The mean age was 61.8 ± 11.63 years old. Patients had been on maintenance hemodialysis for an average of 3.56 years (Table 1). Diabetic nephropathy was the cause of end stage renal disease in 52 patients while 99 patients had other causes such as chronic glomerulonephritis, hypertension and adult polycystic kidney disease (data not shown). The number of patients with less or more than 2 co-morbidities and other demographic characteristics in patients including annual income and monthly medical expense were also listed on (Table 1).

		Patients	Patients (%)
Sex	Female	64	42
	Male	87	58
Age (years)	<65	31	21
	≥ 65	120	79
Annual income (¥)	<100000	77	51
	≥ 100000	74	49
Medical cost (¥/month)	<1000	14	9
	1000-1999	37	25

	2000-2999	49	32
	>3000	51	34
Underlying disease	Diabetes	52	34
	Others	99	66
Comorbidities	≤ 2	78	52
	>2	73	48
Hemodialysis (years)	<5	109	72
	≥ 5	42	28

Table 1: Social and demographic characteristics of patients.

Among 151 primary caregivers, there were 97 females and 54 males. The mean age was 54 ± 11.63 years old. 141 (93%) caregivers had relationship with patients as spouses, parents, or adult children. The rest of caregivers (n=10, 7%) were mostly siblings and daughter and son-in-laws. 117 out of 151 (77%) caregivers did full-time care for patients and were without or had retired or quitted the job. As shown on (Table 2), 82 caregivers spent 12-24 h a day for care-related activities. However, there were also 38 individuals who spent less than 4 h a day for caregiving.

		Caregivers	Caregivers (%)
Sex	Female	97	64
	Male	54	36
Age (Years)	<65	53	35
	≥ 65	98	65
Marital status	Single	10	6.6
	Married	137	90.7
	Widow	4	2.6
Job	No	116	77
	Yes	35	23
Education	Primary school	11	7.3
	High school	40	26.5
	College	100	66.2
Time (Hours/day)	0-3.9	38	25
	4-7.9	13	8.6
	8-11.9	18	11.9
	>12	82	54.3
Caregiver-patient relationship	Spouse/Parent /Adult child	141	93
	Other relatives	10	7

Table 2: Social and demographic characteristics of caregivers.

Caregiver burden

Zarit score system ZCBS and WHO-5 were used in 151 primary caregivers for hemodialysis patients to assess their quality of life and the status of physical and mental health.

77 out of 151 caregivers (51%) reported mild to moderate burden. Moderate to severe burden was reported in 38 caregivers (25.2%). Age was a contributing factor to care burden. Pearson analysis revealed that there was a moderate correlation between caregiver age and care burden ($r=0.235$, $p<0.01$, Table 3).

Caregivers	ZCBS (log 2)	r, p value
Age: 54 ± 11.6	4.95 ± 0.61	$r=0.235$, $p=0.01$
WHO-5: 14.5 ± 6.5		$r=0.596$, $p=0.001$
The correlation of age and self-perceived well-being, as measured by WHO-5 index with caregiver burden was tested by Pearson's correlation analysis. ZCBS scores were transformed to log 2 value for normal distribution.		

Table 3: Age, self-perceived well-being and caregiver burden.

The educational level of caregiver was also a factor in influencing the degree of burden. The higher educational levels of caregivers as defined by the above college graduate were associated with lesser burden (ZCBS scores, 4.74 ± 0.58 ; vs. 5.09 ± 0.59 in caregivers with lower education levels, $p=0.000$, Table 4). Moreover, the relationship between caregiver and patient played a significant role in affecting the levels of burden. Spouses, parents and adult children felt more stressful and burdened than other caregivers. Additionally, the self-perceived well-being as determined by WHO-5 well-being index was inversely correlated with the score of ZCBS, namely the better WHO-5 score, which suggests a better quality of life was associated with the lesser burden ($r=-0.596$, $p<0.01$, Table 3). Similarly, caregivers who still had job or spent less than 4 h per day in caregiving activities had less self-perceived burden than those who were without job or spent more than 12 h per day in caregiving (Table 4).

	Factors		Case (n)	ZCBS (log 2)	P value
Caregivers	Job	Yes	116	5.03 ± 0.18	0.002
		No	35	4.67 ± 0.61	
	Education	Low	92	5.09 ± 0.59	0.000
		High	59	4.74 ± 0.58	
	Time (hours/day)	<4	38	4.70 ± 0.57	0.048
		4-7.9	13	4.91 ± 0.68	
		8-11.9	18	4.94 ± 0.69	
		>12	82	5.07 ± 0.57	
Patients	Annual Income (¥)	≤ 100000	77	5.08 ± 0.58	0.01
		>100000	74	4.82 ± 0.61	
	Medical cost (¥/month)	≤ 1000	14	4.56 ± 0.36	0.044

		1000-1999	37	5.04 ± 0.56	
		2000-2999	49	4.91 ± 0.63	
		>3000	51	5.05 ± 0.64	
	Underlying disease	Diabetes	52	5.12 ± 0.60	0.015
		Others	99	4.87 ± 0.60	
	Comorbidities	≤ 2	78	4.93 ± 0.58	0.02
		>2	73	5.20 ± 0.63	
	Hemodialysis (Years)	<5	109	4.95 ± 0.61	0.844
		≥ 5	41	4.97 ± 0.61	

Table 4: Social and demographic factors contribute to caregiver burden.

From patients' part, patients with underlying disease of diabetes gave their caregivers more burden than patients with other underlying diseases (Table 4). One reason might be that patients with diabetes had more co-morbidities and might need more assistance in personal life care. Indeed, the caregiver burden was significantly increased in patients with more than two co-morbidities. Patient's income levels and medical expense also had significant impact on caregiver burden. Less caregiver burden was found on patients with high annual income (more than 100 thousands yuan) compared to patients with low annual income. Similarly, the amount of medical expense was positively correlated with the levels of caregiver burden. The burden in caregivers for patients who paid less than one thousand yuan a month in medical expense was lower than the burden in caregivers for patients who paid more ($p<0.05$).

Discussion

It is well recognized now that care for patients with chronic fatal illness by family members has two-opposite impacts on physical and mental health of caregivers. One is positive because the obligation and responsibility to take care the loved-one who may loss in any time would give the caregiver all the inspiration to put out the whole efforts. However, long-term caregiving also have a significantly negative influence [18-21]. The physical, emotional, economical and timing strains may overwhelm the caregivers.

End stage renal disease is still considered as a chronic fatal disease although renal replacement therapy including hemo and peritoneal dialysis has helped to prolong the life and improve the quality of life. About 50% of end stage renal disease patients lost their life after 5 years in hemodialysis in China. Thus, there is always an impending life threatening burden for patients and their caregivers on maintenance hemodialysis. Riou et al., reported that there were 25% of caregivers feeling stressed and 28% of caregivers feeling depressed when they cared for Canadian nocturnal home hemodialysis patients [22]. Caregiving burden was also perceived by patients from the Frequent Hemodialysis Network and by caregivers themselves from a dialysis center in Turkey [23-25]. In this study, 51% of caregivers had mild to moderate and 25.2% of caregivers had moderate to severe self-perceived burden, suggesting a relatively widespread presence of physical and psychological distress in family caregivers for Chinese

patients on maintenance hemodialysis. We have further identified factors in caregivers and patients that might contribute to caregiver burden. We found a linear correlation between age and caregiver burden. Moreover, caregivers who needed to spend more time on caring related activities had increased stress and burden. Similarly, full time caregivers had more burden compared to those who still had a job and did care in part time. The education levels in caregivers also seemed to play a role. Caregivers with college or higher education had less self-perceived burden compared to those with high school or lower education. As expected, the status of physical and mental well-being was negatively correlated with caregiver burden. In term of patient and caregiver relationship, we found that parents, spouses and adult children had higher caregiver burden than other family members. Our results are not in completely agreement with the data from Mollaoglu et al., however. They showed that younger age in caregiver was associated with higher burden and spouses as caregiver had lower burden compared to other family members [25]. These discrepancies in self-perceived caregiver burden between our caregivers and theirs may be caused by culture differences. In addition, since both our study and theirs had a relative small number of subjects, a further increase in research subjects is required to confirm the findings and clarify the differences.

We have also identified disease and social and demographic factors in patients that were related to caregiver burden. For instance, patient's underlying diseases, co-morbidities, annual income and medical expense had significant impact on caregiver burden. Patients with diabetes and more co-morbidity caused higher burden in caregivers. Understandably, lower income and more medical expense were associated with higher burden. These social and economic factors have also been shown to contribute to depression and caregiver burden in patients on maintenance hemodialysis and their family caregivers by other group [26].

In conclusions, we reported for the first time the presence of a relative high physical and mental burden in family caregivers of Chinese patients on maintenance hemodialysis. Factors in caregivers such as the age, education level, with or without job, caring hours, patient and caregiver relationship and the status of physical and mental well-being were identified to contribute to caregiver burden. Patient's underlying disease, number of co-morbidities, and income and medical expense also played a role.

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