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BURDEN OF CARE ON FAMILY CAREGIVERS OF PATIENTS UNDERGOING RENAL REPLACEMENT THERAPIES

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ABSTRACT

Background and Purpose: Burden of care of patients undergoing renal replacement therapies is principally borne by the family. Since renal replacement therapies has got a distinctive nature, the burden of care on family caregivers is not the same. This burden of care can reduce the quality of taking care of patients, cause various complications and increase pressure on healthcare system. Therefore, the present study intended to determine and compare the burden of care on the family caregivers of patients undergoing hemodialysis, peritoneal dialysis and kidney transplant. Materials and Methods: The present research was a descriptive-comparative study on 210 family caregivers of patients undergoing hemodialysis, peritoneal dialysis and kidney transplant in the hospitals affiliated to Isfahan University of Medical Sciences in 2016. Simple sampling method was performed and data were collected using demographic indormation questionnaire and Novak's and Guest Caregiver Burden Inventory (CBI). Then, data were analyzed by performing the statistical tests of one-way ANOVA, T-independent test, Spearman Correlation Coefficient and Pearson Correlation Coefficient in $SPSS_{18}$ statistical software.
Results: the mean caregiver burden in terms of time-dependent, developmental and physical and burdens as well as the overall score of burden of care was higher on the family caregivers of patients undergoing hemodialysis and lower on the family caregivers of patients undergoing kidney transplant than other renal replacement therapies. However, not any statistically significant difference was observed between the therapy groups of by moderating the confounder variables of caregiver's age, patient's age, duration of treatment, and dependency of the patient on the caregiver ($P>0.05$). There was not any statistically significant difference between the groups in terms of social and emotional burdens ($P>0.05$). The overall caregiver burden had a direct and positive relationship with caregiver's age, patient's age, duration of treatment, and dependency of the patient on the caregiver ($P<0.05$) while it had a negative relationship with the educational level of caregiver. There was not any statistically significant difference between the total score of burden of care on male and female caregivers; the burden score was lower on employee caregivers and higher on spouse caregivers than other caregivers. However, not any statistically significant difference between them by moderating the confounder variable of caregiver age and educational level ($P>0.05$).
Conclusion: The burden of care was higher on the family caregivers of patients undergoing renal replacement therapies esp. hemodialysis, caregivers of elder patients, caregivers of patients undergoing long-term treatment, elder caregivers and spouse caregivers in terms of time-dependent, developmental, physical, social and emotional burdens. Therefore, these caregivers should be supported by the members of medical treatment team.

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Introduction

Renal replacement therapies including hemodialysis, peritoneal dialysis and kidney transplant are used to prevent uremia and its complications in the patients with end-stage kidney failure[1] [1]. Although these therapies improve the symptoms and prolong the longevity of these patients, they cause many complications that requires taking permanent care of these patients [2]. In today's healthcare systems, the major care of chronic patients is undertaken by the patients themselves and their

[1] End-stage renal disease (ESRD)

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families and patients' home is considered as a healthcare center; that means hospitals has an unremarkable role in this regard [3].

Family is the most important unit in the society in terms of one's health state and adaptability to difficult conditions such as illness and treatment [4] and patients undergoing renal replacement therapies are no exception. With respect to the fact that the major care of these patients are taken at their homes, the incurred burden of care can endanger the caregivers' health and sufficient care may not be given to the patients; This issue decreases adherence to treatment, disrupts medication and dietary, causes frequent referrals and hospitalizations of patients in the hospital, increases the burden of healthcare system and reduces patients' quality of life. Therefore, identification of the burden of care on family caregivers can play a decisive role in improving their health and the patients' health [5]. Penkert and Sorenson believe that patients who enjoy family support have longer life and better adaptability to the disease [6]. Thus, the psychophysical and social health states of family caregivers is greatly important and the members of medical treatment team esp. nurses, should strive to achieve it [3,7].

Since the three type of renal replacement therapies have distinctive nature, they are definitely associated with different burden of care on family caregivers. However, since taking care of patients is a value in Iranian culture, caregivers may not consider the burden they incur due to the long course of chronic kidney disease, complications of treatment, patients' new needs, fundamental changes in lifestyle and the persistent care of their physical, psychological and social states as a real burden. Thus, under the influence of this burden, their health is endangered in different dimensions. Despite several studies on the burden of care on family caregivers of patients undergoing one of the renal replacement therapies conducted in Iran and throughout the world [8, 9, 10 & 11], the present study intended to determine and compare the burden of care on family caregivers of patients undergoing renal replacement therapies.

Materials and Methods

The present research was a descriptive-comparative study performed in the hemodialysis, peritoneal dialysis and kidney transplant units of all Nour, Hazrat-e-Aliasghar (PBUH), Al-Zahra (PBUH) and Amin hospitals of Isfahan in 2016.

About 210 family caregivers of patients undergoing hemodialysis, peritoneal dialysis and kidney transplant participated in this study; The caregivers, who were responsible for taking care of non-hospitalized patients with at least three months of renal replacement therapies, were above 18 years old, lived with the patients, and had no history of chronic or mental diseases.

The participants completed demographic information questionnaire consisted of information about the age, sex, occupation and educational level of the caregiver, relation of caregiver with the patient as well as information about patients' duration of treatment with the current therapies, and dependency of patient on the caregiver, and Novak's and Guest Caregiver Burden Inventory (CBI). The validity and reliability of this questionnaire was assessed by McCleary et al. (2007). In Iran, Abbasi et al. (2011) translated the questionnaire from English to Persian and the Persian version of the questionnaire was translated to English once more by an English language translator. Once the questionnaire was reviewed to eliminate the gaps, a pilot study was administered on 20 caregivers of patients with cancer. The Cronbach's Alpha coefficient of the whole CBI scale was estimated as %90 while the Cronbach's Alpha coefficient of the sub-scales ranged from 26 to 82 percent.

The CBI comprised 24 items with 5 subscales including time-dependent burden (items 1 to 5), developmental burden (items 6 to 10), physical burden (items 11 to 14), social burden (items 15 to 19) and emotional burden (items 20 to 24). The responses of caregivers were scaled on 5-point Likert's scale (Completely False to Completely True). While answering the questionnaire, the respondents selected one of options from completely false (0), false (1), partly true (2), true (3), and completely true (4). Then, data were analyzed by performing the statistical tests of one-way ANOVA, T-independent test, Spearman Correlation Coefficient and Pearson Correlation Coefficient in $SPSS_{18}$ statistical software. The different dimensions of burden of care were compared and the relationship between background features and mean score of burden of care was investigated.

Moral Considerations

The present study was conducted with the permission of Isfahan University of Medical Sciences. The purpose of the study was explained to the patients and caregivers. Then, informed written consent was reached from the caregivers and they were ensured of the confidentiality of their personal information.

Results

About %64.3 of the caregivers of patients undergoing hemodialysis, %66.7 of the caregivers of patients undergoing peritoneal dialysis and %66.7 of the caregivers of patients undergoing kidney transplant were female. The results of Chi-square test showed that there was not any statistically significant difference between frequency distribution of caregivers' sex ($P>0.05$).

The mean age of the caregivers of patients undergoing hemodialysis was 47.1±13.8, peritoneal dialysis was 42.3±12.5, kidney transplant was 41.8±11.8. The mean duration of treatment of patients undergoing hemodialysis was 48.3±25.4, peritoneal dialysis was 39.7±14.4, kidney transplant was 22.9±14.5. The mean age of patients undergoing hemodialysis was 59.5±14.4, peritoneal dialysis was 54.9±15.5, kidney transplant was 40.9±14.8. The results of one-way ANOVA showed that there was a statistically significant difference between the mean age of caregivers, age of patients and duration of treatment, and Kruskal-Wallis test indicated that there was a statistically significant difference between the dependency of patients to

the caregivers in all three therapy groups (P<0.05). (Table 1) presents the frequency distribution of other background features.

Table 1: Frequency distribution of background features

Therapy Groups / Background Features		Hemodialysis		Peritoneal Dialysis		Kidney Transplant	
		Number	Percentage	Number	Percentage	Number	Percentage
Hospital	Nour and Hazrat-e-Aliasghar (PBUH)	29	41/4	26	37/1	24	34/3
	Amin	31	44/3	0	0	0	0
	Al-Zahra (PBUH)	10	14/3	44	62/9	46	65/7
Occupation of Caregiver	Housewife	43	61/4	44	62/9	35	50
	Employee	10	14/3	11	15/7	12	17/1
	Other	17	24/3	15	21/4	23	32/9
Relation of Caregiver	Spouse	28	40	27	38/6	33	47/1
	Mother	4	5/7	6	8/6	12	17/1
	Father	1	1/4	3	4/3	4	5/8
	Other	37	52/9	36	51/5	21	30
Educational Level of Caregiver	Illiterate	10	14/3	5	7/1	3	4/3
	Elementary	18	25/7	15	21/4	25	35/7
	Diploma	24	34/3	31	44/4	20	28/6
	University	18	25/7	19	27/1	22	31/4
Dependency of Patient to the Caregiver	Very High	34	48/6	29	41/4	6	8/6
	High	19	27/1	19	27/1	6	8/6
	Medium	15	21/4	15	21/4	26	37/1
	Low	2	2/9	7	10	25	35/7
	Very Low	0	0	0	0	7	10

The results of one-way ANOVA showed that there was a statistically significant difference between the mean burden of care in three therapy groups in terms of time-dependent, development and physical burdens (P<0.05). However, not any significant difference was observed between the therapy groups by moderating the confounder variables (caregiver's age, patient's age, duration of treatment, dependency of patient on caregiver) based on ANCOVA (P>0.05). Furthermore, the results of one-way ANOVA and ANCOVA showed that there was not any statistically significant difference between the mean score of burden of care in terms of social and emotional burden in all three therapy groups (P>0.05). The results of ANOVA showed a statistically significant difference between the overall score of burden of care in all three therapy groups. However, this difference was not significant by moderating the confounder variables based on the results of ANCOVA (P>0.05) (Table 2)

Table 2: Comparison of mean burden of care in terms of different areas between caregivers of all three therapy groups

Therapy Groups / Background Features	Hemodialysis		Peritoneal Dialysis		Kidney Transplant		ANOVA		ANCOVA	
	M	SD	M	SD	M	SD	F	P	F	P
Time-dependent	13/2	4/9	12/6	5/6	5/6	5/1	47/1	/001 <0	3/02	/051 0
Developmental	11/8	5/5	9/2	6/1	8/7	5/3	6/01	/003 0	2/71	0/07
Physical	8/1	4/7	6/3	4/6	5/2	4/2	6/32	/002 0	1/74	0/18
Social	9	4/5	7/7	4/7	7/5	4/2	2/43	0/09	0/92	0/40
Emotional	5/6	4/3	5/1	4/1	4/9	3/9	0/64	0/52	0/29	0/75
Overall	4/7	17/2	40/8	20/4	31/8	17/8	/99 12	/001 <0	1/28	0/28

Pearson correlation showed that the overall caregiver burden had a direct and positive relationship with caregiver's age, patient's age, duration of treatment, and dependency of the patient on the caregiver (P<0.05) while it had a negative

relationship with the educational level of caregiver. There was not any statistically significant difference between the total score of burden of care on male and female caregivers based on T-independent test (P>0.05). According to one-way ANOVA, the burden score was significantly lower on employee caregivers than other caregivers (P<0.05). ANCOVA showed that there was not any statistically significant difference between the mean overall score of burden of care of caregivers and their occupation by moderating the confounder variable of educational level (P>0.05). Furthermore, the results of one-way ANOVA showed that the mean overall score of the burden of care was not the same between different relations of caregivers with the patients. However, ANCOVA showed that not any significant relationship was observed in this regard by moderating the confounder variable of caregiver's age (P>0.05) (Table 3).

Table 3: Comparison of the relationship between mean overall score of burden of care and background features

Factors		M	SD		
Caregiver's sex	**Male**	39/7	18/4		
	Female	40/4	20/2		
Relation of Caregiver with Patient	**Spouse**	45/8	18/8	**ANOVA**	**ANCOVA**
	Mother	37/8	20/9	F=5/07 P=0/002	F=1/85 P=0/14
	Father	43/9	15/4		
	Other	34/9	19		
Occupation of Caregiver	**Housewife**	42/6	19/9	F=3/07 P=0/48	F=0/89 P=0/41
	Employee	33/7	19/2		
	Other	38/4	18/1		
Caregiver's Age (Year)		r=0/293	p <0/001		
Duration of Treatment (Month)		r=0/209	p =0/003		
Patient's Age		r=0/153	p =0/03		
Educational Level of Caregiver		r=-0/183	p =0/008		
Dependency of Patient on Caregiver		r=0/576	p <0/001		

Discussion

The present study intended to determine and compare the burden of care on the family caregivers of patients undergoing hemodialysis, peritoneal dialysis and kidney transplant. The results indicated that the burden of care were higher on the caregivers of patients undergoing hemodialysis than the other two therapy groups in time-dependent, developmental and physical terms while these burdens were lower on the caregivers of patients undergoing kidney transplant than the other two therapy groups.

In terms of time-dependent burden of care, Lu et al. (2015) and Akpinar et al. (2011) showed that the burden of care on the caregivers of patients with musculoskeletal and Alzheimer's diseases was equal to the caregivers of patients undergoing hemodialysis in time-dependent term. Bademly et al. (2016) showed that time-dependent burden of care was lower on the caregivers of patients with Schizophrenia than the caregivers of patients undergoing hemodialysis and peritoneal dialysis while it was higher than the caregivers of patients undergoing kidney transplant. This difference may contribute to the different type of diseases investigated in both studies.

The caregivers of patients undergoing hemodialysis had to spend much time to commute to the hospital while the caregivers of patients undergoing peritoneal dialysis spent much time for dialysis at home. On the contrary, the patients undergoing kidney transplant were less dependent on their caregiver after at least three months, as an inclusion criterion, and their caregivers did not have to spend much time to take care of their patients.

In terms of developmental burden of care, the findings of Akpinar et al. (2011) and Dademly et al. (2016) indicated that the developmental burden of care was higher on the caregivers of patients with severe Schizophrenia and Alzheimer's diseases than the caregivers of patients undergoing hemodialysis in the present study. On the other hand, Moeini et al. (2012) showed that the developmental burden of care was lower on the caregivers of patients undergoing CABG[2] than the caregivers of patients undergoing all three types of renal replacement therapies in the present study. This difference may contribute to the

[2] Coronary Artery Bypass Grafting

fact that CAD[3] is often an acute disease that does not involve the caregiver patient care for a longer time. Nevertheless, the caregivers of patients undergoing renal replacement therapies are involved in taking care of their patients and their complications and problems for months and even year; Therefore, different developmental stages of the caregivers' life are influenced by patient care.

In terms of physical burden of care, the findings of Akpinar et al. (2011) showed that higher physical burden of care on the caregivers of patients with Alzheimer's disease was as much as the burden of care on the caregivers of patients undergoing hemodialysis, which was in line with the results of the present study. On the contrary, Chiang et al. (2010) showed that lower physical burden of care on the caregivers of patients with heart failure than the caregivers of all three therapy groups in the present study. This difference may be due to the need for more physical care in patients with kidney failure and the complications of renal replacement therapies than heart failure. Taking care of patients undergoing hemodialysis which require frequent transfer of the patient to the hospital for HD[4] and companionship of caregiver for occasional hospital admissions as well as care of patients undergoing peritoneal dialysis which require displacement and carriage of bags of dialysate solutions and performing dialysis four times a day in the long run put higher physical burden on the caregivers [1,13].

In terms of social burden of care, there was not a significant difference between the mean score of burden of care in all three therapy groups. Drury et al. (2014) showed that social burden of care on the caregivers of patients with hoarding disorder was almost equal to the social burden of care on the caregivers of patients undergoing peritoneal dialysis. On the contrary, Chiang et al. (2010) showed lower social burden of care on the caregivers of patients with heart failure than the caregivers of all three therapy groups in the present study. This difference was predictable because patients with a chronic and degenerative disease like kidney failure and renal replacement therapies not only need more care than patients with heart failure but also have more severe negative impact on the social activities and life of the caregivers. The caregivers of patients undergoing renal replacement therapies cannot generally participate in many events, trips and social activities due to the considerable time they have to spend for patient care and treatment affairs; Thus, they have to incur social burden of care [14,15].

In terms of emotional burden of care, Drury et al. (2014) and Apkinar et al. (2011) found higher emotional burden of care on the caregivers of patients with hoarding disorder and Alzheimer's disease in comparison to the caregivers in the present study. the results of Bademly et al. (2016) showed that the emotional burden of care was higher on the caregivers of patients with Schizophrenia than the caregivers of all therapy groups in the present study; This may be due to the severe emotional burden that taking care of patients with mental diseases imposes on the family esp. primary caregiver.

On the contrary, Farahani et al. (2016) and McCleary et al. (2006) found lower emotional burden of care on the caregivers in their study than the caregivers in the present study. The inconsistence between the present study and findings of Farahani et al. may contribute to the different sampling conditions (inclusion of caregivers who had not had any serious problems in their family in Farahani's study versus the absence this criterion in the present study) and the inconsistence with McCleary's et al. findings may be due to the difference in the type and stage of disease (determination of burden of care in the early stages of psychosis in McCleary's study versus determination of burden of care after at least three months prior to the onset of renal replacement therapies in the present study).

Interestingly, the type of renal replacement therapies did not have any impact on the emotional burden of care in this study. It seems that the emotional burden of care caused by the disease of a family member, requiring lifelong therapy and leading to patient's death if not treated thoroughly, was almost the same in all three therapy groups in this study.

The results of the present study indicated that the overall burden of care was significantly higher on the caregivers of patients undergoing hemodialysis than the caregivers of patients undergoing peritoneal dialysis. Furthermore, the overall burden of care was significantly lower on the caregivers of patients undergoing kidney transplant than the caregivers of patients undergoing peritoneal dialysis.

According to the findings of Bademly et al. (2016), Chiang et al. (2010) and Drury et al. (2014), the overall burden of care was lower on the caregivers of patients with Schizophrenia, heart failure and hoarding disorder than the caregivers of patients undergoing hemodialysis in the present study while it was higher than the overall burden of care on the caregivers of patients undergoing peritoneal dialysis and kidney transplant. This difference may contribute to the different type of diseases investigated in the aforesaid studies in comparison to the present study.

Considering the variables of caregiver's age, patient's age, duration of treatment and dependency of patient to the caregiver, there was a statistically significant difference between the time-dependent, developmental, physical and overall burden of care on the family caregivers of all three therapy groups participated in this study.

The results of the present study indicated that there was a direct relationship between the burden of care and caregiver's age, duration of treatment and patient's age. Like the present study, Abbasi et al. (2011) found higher overall burden of care on elder caregivers of patients undergoing hemodialysis than other caregivers. Elder caregivers incur higher burden of care, are

[3] Coronary Artery Disease
[4] Hemodialysis

physically more affected, change the type of their physical activity and are psychologically more vulnerable than young caregivers due to their isolation from social activities [16-19].

In terms of duration of treatment, the results of Salmani et al. (2013) and Abbasi et al. (2011) indicated that there was a direct relationship between duration of disease treatment and the mean burden of care.

Salmani et al. (2013) also found that there was a direct relationship between the mean burden of care and patient's age. That is, the older the patient, the higher his care needs will be. Furthermore, increased patient's age is often associated with increased mood disorders and complications of treatment [19-21].

The results of the present study showed that there the overall burden of care had a negative relationship with educational level of the caregiver while it has a direct positive relationship with dependency of patient on the caregiver. Unlike the present study, Salmani et al. (2013) found a statistically insignificant relationship between the burden of care and educational level of the caregiver. This difference may contribute to the different sample size in both studies (60 in Salmani's study versus 210 in the present study). Moreover, according to the results of the present study, the higher the educational level of the caregiver, the better his adaptability to the conditions. That's because caregivers with higher educational levels have higher analytical thinking ability that moderates the burden of care imposed on them. On the other hand, caregivers with higher educational levels have better job and higher income; therefore, their economic stability plays a crucial role in improving the adaptability of the caregiver and family to cope with the problems.

In terms of dependency of patient on the caregiver, the study of Abbasi et al. (2013) on the caregivers of patients with cancer and his another study (2010) on the caregivers of patients undergoing hemodialysis showed that there was a direct relationship between the burden of care and dependency of patient of the caregiver.

Based on the findings of the present study, the mean score of overall burden of care was higher on female than male caregivers while not indicating a statistically significant difference between both sexes. In Abbasi's et al. (2013) study, the relationship between these two sexes was not significant.

Besides, the present study showed that employee caregivers incurred lower burden of care; however, not any significant relationship was found between the mean score of overall burden of care and the occupation of caregivers by moderating the confounder variable of educational level of caregivers. On the contrary, Abbasi et al. (2013) observed no relationship between the burden of care and occupation of caregivers. This difference may be due to the different sample size in both studies.

Comparing the overall burden of care with the relation of caregiver to the patients, it was found that spouse caregivers incurred higher burden of care; Nevertheless, their relationship remained insignificant by moderating the confounder variable of caregiver's age. The results of Abbasi et al. (2013) and Salmani et al. (2013) on the caregivers of patients with cancer indicated that the burden of care was higher on spouse caregivers. It seems that the spouses of patients have different roles in the society and home, and are responsible for the duties of their patients after the disease. That's why they incur higher burden of care and are more under pressure.

Conclusion

The overall findings of the present study indicated that the burden of care was higher on the family caregivers of patients undergoing renal replacement therapies esp. hemodialysis, caregivers of elder patients, caregivers of patients undergoing long-term treatment, elder caregivers and spouse caregivers in terms of time-dependent, developmental, physical, social and emotional burdens. Therefore, these caregivers should be supported by the members of medical treatment team including nurses, physicians, social workers, psychologists and clergymen.

The limitations of the current study included lack of easy access to the families and caregivers of patients undergoing renal replacement therapies esp. kidney transplant, as well as the limited time allocated to the thesis.

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Conflicts of interest

The authors have no conflicts of interest.

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