

## ORIGINAL ARTICLE

**Factors Affecting the Burden on Family Caregivers of ESRD Patients**Rabin F<sup>1</sup>, H Hoque E<sup>2</sup>, Ahmad SN<sup>3</sup>, Shikder S<sup>4</sup>**Abstract:**

*Patients of chronic kidney disease on hemodialysis face varieties of challenges and comorbid conditions need regular assistance from family caregiver. Caregivers of end stage renal disease (ESRD) have to bear loads of patient's daily activities, cares, medication, carrying to hospital, managing their psycho-social and financial demands which impose additional stress and burden among them. The study was conducted to evaluate the effect of care giving of patients with ESRD and to analyze the factors associated with it. This cross sectional, observational and descriptive type of study was conducted in the Department of Nephrology and Psychiatry of Holy Family Red Crescent Medical College during the period of July 2018 to June 2019. Fifty family caregivers of age more than 18 years providing care or assistance to a relative with ESRD on dialysis were included. The burden of the care giver was assessed by a verified and culturally adopted Bangla-version of 22 factor Zarit Burden Interview (ZBI-B) scale. Difference of burden was not statistically significant considering its sex, marital status, place of residence, education level, religion, relation with patient, living in same house with patient or duration of the care giving of the patients ( $p>0.05$ ). In 50% cases care givers had little or no burden, 26% mild to moderate, 22% moderate and 2% severe burden. So, in Bangladesh caregiving to ESRD patients imposes no or little burden on majority of family caregivers.*

**Keywords:** Caregiver, ESRD, Family Burden

1. Associate Professor and Head of Psychiatry, Holy Family Red Crescent Medical College, Dhaka.
2. Professor and Head of Nephrology, Holy Family Red Crescent Medical College, Dhaka.
3. Assistant Professor of Medicine, Holy Family Red Crescent Medical College, Dhaka.
4. Assistant Professor of Nephrology, Holy Family Red Crescent Medical College, Dhaka.

**Introduction:**

Worldwide number of patients with chronic kidney diseases (CKD) are increasing over last decades, in 2015 globally 1.2 million patients died from CKD which is a 32% higher than the death of 2005<sup>1</sup>. Globally 5.3 to 10.5 million patients of CKD need some forms of renal replacement therapy and many of other ESRD patients die due to resource constrains<sup>2-3</sup>. The number of CKD and

patients taking hemodialysis are increasing dramatically in Bangladesh<sup>4-5</sup>. CKD and ESRD are more common among elderly population aged above 65 years<sup>6</sup>. Diabetes mellitus, hypertension, cardiovascular diseases, metabolic bone diseases and stroke are the established comorbid medical conditions of CKD those need additional care<sup>7-8</sup>.

Such a chronic disease that needs regular hemodialysis and additional care like carrying to the hospital, care for comorbid conditions, managing psycho-social and financial issues may impose additional burden over family caregiver. The burden of caregiving responsibilities has been shown to influence the quality of the relationship between caregivers and care receivers, caregiver health, and the decision to institutionalize the care receiver<sup>9</sup>.

Family caregivers are essential partners in the delivery of complex health care services. Unlike professional caregivers such as physicians and nurses, informal caregivers, typically family members or friends, provide care to individuals with a variety of conditions such as advanced age, dementia and cancer. Caregiver burden has been defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual. Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers<sup>10-11</sup>. Burden is not a unidimensional measure rather a multidimensional construct<sup>12</sup>. In Bangladesh like other Asian countries patients of chronic disabling diseases care is given by family members carrying physical, financial, social and emotional loads. The Zarit Burden Interview (ZBI), is the most commonly used scale to measure the caregiver burden among caregivers of chronic disease. It provides a comprehensive assessment of both objective and subjective burden, is one of the most commonly used burden measures<sup>13</sup>. This cross sectional study was conducted to see the level of burden among caregivers of patients with ESRD on dialysis using Bangla version of Zarit Burden Interview (ZBI-B)<sup>14</sup>. Every month approximately 450 to 500 patients of ESRD visit the department for hemodialysis in Holy Family Red Crescent Medical College Hospital. Most patients are accompanied with one or more caregiver, so it was an ideal place to interact with caregivers directly and easily.

### **Methodology:**

It was a cross sectional, observational and descriptive type of study conducted in the Department of Nephrology and Psychiatry of Holy Family Red Crescent Medical College to evaluate the effect of care giving of patients with ESRD and to analyze the factors associated with it. Fifty family caregivers of age  $\geq 18$  years providing care or assistance to a relative with ESRD on dialysis were selected. Providing care was defined as attending to the needs of the patients with ESRD, accompanying him/her to the doctor's appointments and transportation to the dialysis center, helping with administration of medication, helping with housework, mobility, dressing, preparing an appropriate renal diet and activities of daily living. Domestic maids employed to help care for patients with ESRD were excluded from the study. Before inclusion in the study the detail aims, objectives, methodology was explained to both the respective patient and the caregiver then verbal and written informed consent was taken. The interview was taken with a completely unbiased environment (away from the patient and other family members) to express their feelings and experience with full confidentiality. The burden of the care giver was assessed by a verified and culturally adopted Bangla-version of 22 factor Zarit Burden Interview (ZBI-B) scale. The care givers were asked to self-administer the ZBI-B questionnaire. Data analysis was performed by statistical package for social science (SPSS), version-17.

### **Results:**

Mean age of the patients was  $54.86 \pm 13.02$  (24-74) years. Among them 64% were male and 36% female. Eight percent was illiterate, twenty percent had primary education, thirty eight percent secondary, twenty percent graduate and fourteen percent were post graduate. Mean age of the caregivers was  $35.54 \pm 11.23$  (15-61) years. Among them 46% were male and 54% female.

Eighty six percent were from urban area and fourteen percent from rural area. Relationship of the caregivers to the patients were as follows mother 16.0%, father 14.0%, wife 24.0%, husband 16.0%, daughter 8.0%, son 12.0% and others 10.0%.

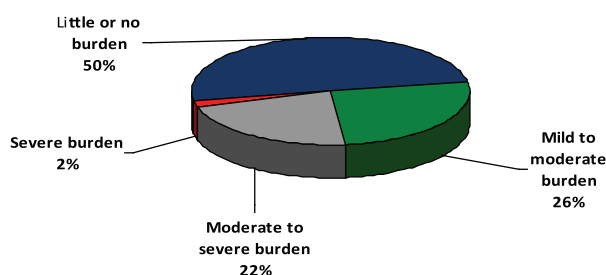
**Table I:** Differences in burden of caregiving according to ZBI-B score and demographic characteristics (n=50)

Variables	Mean ± SD	Test value	p value
<b>Sex</b>			
Male	26.13 ±16.01	0.054 <sup>a</sup>	0.957
Female	26.41 ±19.84		
<b>Place of residence</b>			
Urban	27.00 ±18.99	0.697 <sup>a</sup>	0.489
Rural	21.86 ±9.69		
<b>Marital status</b>			
Married	29.06 ±19.02	1.927 <sup>a</sup>	0.062
Unmarried	19.80 ±13.83		
<b>Education level</b>			
Primary	29.25 ±20.19	0.790 <sup>b</sup>	0.506
Secondary	24.00 ±12.56		
Graduate	24.37 ±20.87		
Post graduate	34.75 ±21.35		
<b>Religion</b>			
Islam	27.11 ±18.32	1.161 <sup>b</sup>	0.322
Hindu	11.33 ±3.79		
Christian	33.00 ±4.01		
<b>Relation with patients</b>			
Parents	26.47 ±17.27	0.319 <sup>b</sup>	0.811
Spouse	28.20 ±18.57		
Son/daughter	21.40 ±17.94		
Others	27.80 ±21.95		
<b>Living in same house with patient</b>			
Yes	25.12 ±17.22	1.137 <sup>a</sup>	0.261
No	33.43 ±22.36		
<b>Duration of the care giving of the patients</b>			
6months-1year	25.14 ±15.26	0.278 <sup>b</sup>	0.758
1-3years	30.33 ±24.84		
>3years	25.92 ±19.29		

aIndependent t-test values. bF-values from one-way ANOVA.

Eight percent of caregivers had primary education, 38% had secondary, 38% graduation and 16% were post graduate. Regarding occupation of the caregivers 30.0% unemployed, 12.0% business man, 10.0% student, 38.0% housewife, 2.0% laborer, 4.0% retired, 2.0% service holder and 2.0% others. Family type of the patients was joint 28.0% and single 72.0%. Seventy percent were married and thirty percent unmarried. Eighty six percent of care givers were living in same house with patient, 26% also provide care giving for other patient and 88% had no experience of care giving for same type of patient. Duration of care giving of the patient was 6 months-1year in 56.0%, 1-3 years 18.0% and >3years 26.0%. Among them 78.0% were main care giver; in 12.0% they provide service for <2 hours, 42.0% 2-6 hours and 46.0% >6 hours . Difference of burden was not statistically significant considering its sex, marital status, place of residence, education level, religion, relation with patients, living in same house with patient or duration of the care giving of the patients, 50% cases caver givers had little or no burden, 26% mild to moderate, 22% moderate and 2% severe burden (Table-I, Fig-1).

**Figure 1:** Distribution of severity of burden according to ZBI-B score (n=50)



**Discussion:**

Globally the incidence and prevalence of CKD and ESRD are increasing which also creating extra burden of hemodialysis<sup>15</sup>. The prevalence of CKD rises dramatically with age<sup>16</sup>. The elderly represent the fastest growing group with ESRD, the numbers

of incident ESRD patients over the age of 75 more than doubled number aged 20-64 years<sup>17</sup>. In the current study mean age of the patients taking dialysis was 54.86 ( $\pm$  13.02) years with a range 24-74 years. Patients of CKD on dialysis suffer with many mental, physical and psychological comorbidities. These Comorbidities and factors impose additional psycho-socio-cultural problems for their family and caregivers<sup>18</sup>. Caregivers who are advanced in age, women and co-residents experience greater burden than young, male caregivers and those who live apart from the care-recipient<sup>19-20</sup>.

In Asian countries like Bangladesh care for any chronic disease most of the care duty done by adult family members including husband, wife, partner, significant other, son, daughter but take on the identity of "caregiver"<sup>21</sup>. Older caregivers usually have a better physical, emotional, and cognitive health status and reduced mortality compared to non-caregivers, since the positive aspects of caregiving may create a sense of meaning, emotional closeness, and a purpose for their life<sup>22</sup>. Majority of the caregivers in this study were of older age.

Caregivers assist patients of hemodialysis helping their day to day works, household tasks, and personal care, such as bathing, cleaning and dressing, while they undertake responsibility for financial and technical health procedures in dialysis<sup>23</sup>. In our social structure family obligation and gender norming creates a system of assumptions, beliefs and values that female family members are expected to take the role of care giver<sup>21</sup>. Spouses of patients on dialysis feel isolated due to the loss of social activity, their increased workload, and their negative economic situation. These couples have high rates of depression, sexual problems, and difficulty in communication<sup>24</sup>. Here 40% of caregivers were spouse. Although caregiving is stressful for both genders, it has been found that women are particularly more vulnerable to this process<sup>25</sup>. But in this study no statistical difference of burden was found between two groups. Caregivers of both genders, who live with patients, have higher ratings

of subjective burden, more depressive symptoms, and poorer self-rated health than caregivers who do not live with their patients<sup>26</sup>. In this study nearly all caregivers live with the patients in same residence. In previous studies it was found that they have to spend at least 3 days a week to accompany their patients on haemodialysis<sup>27</sup>. Here among most were main care giver, they provide service for <2 hours in 12%, 2-6 hours in 42.0% cases and >6 hours in 46.0%.

Caregivers' burden was influenced by the relation between the caregiver and the patient, the length of the treatment, and the changes in life<sup>28</sup>. In current study majority of caregivers delivering their service for six months to one years and only 26.0% were engaged for more than 3 years. Caregivers face difficulties with personal and professional life, and work, since they decrease or rearrange their working hours, take days off without pay, stop their job, or retire early in order to provide care to their patient<sup>28</sup>. In the current study 30.0% of the caregivers were unemployed which is consistent with a previous study where same proportion were jobless as they had to contribute about 50 hours a week for caregiving<sup>28</sup>.

Patients from rural areas impose extra negative effects on caregivers for transportation rural to urban dialysis setup occasionally requires change of residence<sup>29</sup>. Here majority (86.0%) respondents were from urban areas. In the current series half of caregivers feel that caregiving creates no or little burden on them. Only 24% caregivers had moderate to severe burden.

### Conclusion:

Caregivers of patient with CKD do not carry significant burden which may be due to socio-cultural background of Bangladeshi population.

**References:**

1. Wang H, Naghavi M, Allen C, Barber RM, Bhutta ZA, Carter A, et al.; GBD 2015 Mortality and Causes of Death Collaborators. Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet*. 2016;388(10053):1459–544.
2. Liyanage T, Ninomiya T, Jha V, Neal B, Patrice HMet al. Worldwide access to treatment for end-stage kidney disease: a systematic review. *Lancet*. 2015;385(9981):1975-1982.
3. GBD 2015 Mortality and Causes of Death Collaborators. Global, regional, and national life expectancy, allcause mortality, and cause-specific mortality for 249 causes of death, 1980-2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet*. 2016;388(10053):1459-1544.
4. Huda MN, Alam KS, Rashid HU. Prevalence of chronic kidney disease and its association with risk factors in disadvantaged population. *Int J Nephrol* 2012;2012:267329
5. Biswas RS, Kashem MA. Etiological Survey of Chronic Kidney Disease Patients on Maintenance Hemodialysis in Different Centers of Chittagong, Bangladesh. *J Integr Nephrol Androl* 2016;3:118-20
6. Selvin E, Manzi J, Stevens LA, Van Lente F, Lacher DA, Levey AS, et al. Calibration of serum creatinine in the national health and nutrition examination surveys (NHANES) 1988-1994, 1999-2004. *Am J Kidney Dis* 2007;50:918-26.
7. Martin KJ, Gonzalez EA. Metabolic bone disease in chronic kidney disease. *J Am Soc Nephrol* 2007;18:875-885
8. Stevens AL, Li S, Wang C, Huang C, Becker BN, Bombardieri AS, et al. Prevalence of CKD and Comorbid Illness in Elderly Patients in the United States: Results From the Kidney Early Evaluation Program (KEEP). *Am J Kidney Diseases* 2010;55:S23-S33.
9. Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: J Gerontol B Psychol Sci Soc Sci*. 2007;62(2):p126–137.
10. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649-55.
11. Carretero S, Garces J, Rodenas F, Sanjose V The informal caregiver's burden of dependent people: theory and empirical review. *Archives of Gerontology and Geriatrics*. 2009;49(1):74–79.
12. Knight BG, Fox LS, Chou CP. Factor structure of the burden interview. *Journal of Clinical Geropsychology*. 2000;6:249–258.
13. O'Rourke N, Tuokko HA. Psychometric properties of an abridged version of the Zarit Burden Interview within a representative Canadian caregiver sample. *The Gerontologist*. 2003;43:121–127.
14. Zarit, SH, Reever, KE, Bach-Peterson, J Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20:649-55.
15. Rabin F, Nahar JS, Mullik MSI, Ahmed HU. Adaptation, linguistic and clinimetric validation of the Bangla version of Zarit Burden Interview. *Bangabandhu Sheikh Mujib Med Univ J*. 2016;9:181-187.
16. Battistella M, Bhola C, Lok CE. Long-term Follow-up of the Hemodialysis Infection Prevention With Polysporin Ointment (HIPPO) Study: A Quality Improvement Report. *Am J Kidney Dis*. 2011;57(3):432-41.
17. United States Census Bureau Population Finder. [cited November 25, 2008]. 2007. Available from: <http://factfinder.census.gov/servlet/SAFFPopulation?sse=on>.
18. Canadian Institutes of Health Information (CIHI) Incident ESRD RRT Patients. 2007 Annual Data Report - Treatment of End-Stage Organ Failure in Canada, 1996 to 2005. [cited October 7, 2008]. 2007. Available from: [http://secure.cihi.ca/cihi-web/products/corr\\_report280208\\_e.pdf](http://secure.cihi.ca/cihi-web/products/corr_report280208_e.pdf).

19. Shahgholian N, Yousefi H. Supporting hemodialysis patients: A phenomenological study. *Iranian Journal of Nursing and Midwifery Research*. 2015;20(5):626-633.
20. Vitaliano PP, Zhang J, Scanlan. Is caregiving hazardous to one's physical health? A meta-analysis. *JM Psychol Bull*. 2003;129(6):946-72.
21. Schulz R and Beach SR. Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA: The Journal of the American Medical Association* 1999; 282 (23):2215–2219.
22. Elise K. Eifert, Rebecca Adams, William Dudley & Michael Perko Family Caregiver Identity: A Literature Review, *American Journal of Health Education*. 2015;46(6):357-367.
23. Given B, Wyatt G, Given C. Burden and depression among caregivers of patients with cancer at the end-of-life. *Oncol Nurs Forum*. 2001;31:1105-1117.
24. EiriniG, Georgia G Caregivers of Patients on Haemodialysis. In: MukadderMollaoglu editor. *Caregiving and Home Care*. Rijeka: Intech Open; 2018:75-84.
25. Khaira A, Mahajan S, Khatri P, Bhowmik D, Gupta S, Agarwal S. Depression and marital dissatisfaction among indian hemodialysis patients and their spouses: A cross-sectional study. *Renal Failure*. 2012;34(3):316-322.
26. Caputo J, Pavalko E, Hardy M. The long-term effects of caregiving on women's health and mortality. *Journal of Marriage and Family*. 2016;78(5):1382-1398.
27. Jadhav B, Dhavale H, Dere S, Dadarwala D. Psychiatric morbidity, quality of life and caregiver burden in patients undergoing hemodialysis. *Medical Journal of Dr D Y Patil University*. 2014;7:722-727.
28. Shdaifat E, Manaf M. Quality of life of caregivers and patients undergoing haemodialysis at Ministry of Health, Jordan. *International Journal of Applied Science and Technology*. 2012;2(3):75-85.
29. Alnazly E. Burden and coping strategies among Jordanian caregivers of patients undergoing hemodialysis. *Hemodialysis International*. 2016;20:84-93.