ORIGINAL ARTICLE

Caregiving Burden And Depression Among Caregivers Of Patient With Epilepsy

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Abstract

Introduction: *The impact of caregiving on caregivers is a significant area to be studied which will directly affect the quality of care given by them to patients with epilepsy. Family caregivers have been described as forgotten patients. The aim of the study was to assess the caregiving burden and depression among caregivers of patient with epilepsy.*

Material And Method: *Descriptive study was conducted among 100 caregivers of adult patients with epilepsy. Samples were selected using purposive sampling. Semi-structured interview schedule, Zarit Burden Interview (ZBI) and Hamilton depression rating scale (HAM-D) were used for data collection. Data was analyzed by descriptive and inferential statistics with SPSS version 20.*

Results: *Among 100 caregivers, 42% reported high mean burden scores on the ZBI and overall 50% of caregivers reported moderate depression on the HAM-D. High level of burden was significantly associated with age of caregivers (p= 0.018) and caregivers' relationship with patients (p= 0.023). The result suggests that there was statistically significant positive relationship on ZBI vs HAM-D (p≤ 0.01).*

Conclusion*: Caregivers of patients with epilepsy experience significant burden while caring for their relatives and level of burden is positively correlated with depression. The study highlights the need for comprehensive care system recognizing caregivers as "co-client".*

Keywords: Caregivers Burden, Depression, Epilepsy, ZBI, HAM-D

INTRODUCTION

Epilepsy was estimated to account for 0.6% of the global burden of disease. Nearly 80% of the people with epilepsy live in low- and middle-income countries. Epilepsy is an unpredictable, often chronic and debilitating disorder that impacts not only those bearing with it but also those who care for them.[1] The prevalence rate of epilepsy in Nepal is 7.3 per 1000 population with the treatment gap of over 80%.[2] Caregiver is anyone, unpaid, who cares for person who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support. At times caregiving results in caregiver burden, which is defines as "a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the caregiving

experience."[3] Meta analyses and other systematic reviews typically conclude that caregivers are more likely to experience depressive symptoms and have poorer health outcomes when compared with various samples of non-caregivers.[4]

A prospective population-based cohort study, from 1993 to 1998 conducted in USA showed that out of 392 caregivers and 427 non-caregivers, after 4 years of follow-up, 103 participants (12.6%) died. Participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non-caregivers (relative risk [RR], 1.63; 95% confidence interval [CI], 1.00-2.65). The study concluded that being a caregiver who is experiencing mental or emotional strain is independent risk factors for mortality among

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caregivers.[5] A descriptive study conducted in Chandigarh, India in 2014 to assess the problems, awareness and practices of caregivers of epileptic patients regarding home management of epilepsy showed that among 60 caregivers more than half of the caregivers (51.7%) felt stressed regarding caring for their relative. Around one fourth of the caregivers (28.3%) felt that their social life had suffered because they were caring for their relatives.[6]

A prospective study was conducted in Nepal in 1999 to study patients with epilepsy attending T.U. teaching hospital among 287 patients which showed that majority (91.98%) of patients were less than 40 years of age. More than half of the patients were single and only one-fourth of the patients sought treatment within one month. Study suggested need got general public awareness to destigmatize the disease for early recognition and treatment.[7] This stigma also added to the caregiver burden.Yet contrary to other chronic medical and neurological conditions, much of the literature on epilepsy burden and impact on quality of life focuses on the patient as the "client" and fails to see caregivers as a "co-client", particularly for adult epilepsy. The aim of the study was to assess caregiving burden and depression among caregivers of patient with epilepsy.

MATERIAL AND METHOD

A descriptive cross-sectional study was conducted among 100 caregivers of patients with epilepsy. Samples were selected using purposive sampling technique from the psychiatric, neurology and medicine OPD of Universal College of Medical Sciences-Teaching Hospital (UCMS-TH), Rupandehi. Written informed consent was obtained prior to data collection from each respondent fulfilling inclusion criteria. Data was collected during 6months period (March, 2019 to September, 2019). Semi-structured interview schedule, standardized scales Zarit Burden Interview (ZBI) [8] and Hamilton depression rating scale (HAM-D) [9] were used for data collection. The scales were in English language so; translation and back translation was done to develop scales in Nepali language.

Semi-structured interview schedule was used to collect data regarding socio-demographic characteristics of caregivers of patients with epilepsy. Zarit Burden Interview (ZBI) is a 22-item inventory derived from the original 29-item inventory. It is the most widely used standardized, validated scale to assess caregiver burden, administered previously in various neurological disorders, including epilepsy. The 22 items evaluate the effect of disease on the caregiver's QOL, psychological suffering, financial difficulty, shame, guilt, and difficulty in social and family relationships. Scores range from 0 to 88 with higher scores indicating higher burden (<20: little or no burden, 21–40: mild-to-moderate burden, 41–60: moderate-to severe burden, 61–88: severe burden). Hamilton depression rating scale (HAM-D) has proven useful for many years to determine patient's level of depression. It contains 21 items in the list and the scoring is based on the first 17 items only. It generally takes 15-20 minutes to complete the interview and score the results. Eight items are scored on a 5-point scale, ranging from 0= not present to 4=severe. Nine are scored from 0-2. Sensitivity: 86.4% and specificity: 92.2%. Administrative and ethical approval was obtained from the concerned authorities of Universal College of Medical Sciences-TH prior to data collection. Descriptive statistics (frequency, percentage, mean and standard deviation) and inferential statistics (Chi-square tests and Karl Pearson's coefficient correlation for association) were used with SPSS version 20 for data analysis.

RESULT

Regarding socio-demographic variables among 100 caregivers, 65% were female, 40% were of age group 30-39years, 62% were married, 80% were literate, 63%were employed and having self-employment, 60% Hindu, 54% were from joint family and 44% were parents.

The results showed that caregivers (42%) reported high mean burden scores on the ZBI and overall 50% of caregivers reported moderate depression on the HAM-D.

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Table 1: Association between socio-demographic variables and level of burden among caregivers of patients with epilepsy (N=100)

Socio-demographic variables	Level of burden				χ^2	p-value
	Little/No	Mild	Moderate	Severe		
	No. (%)	No. (%)	No. (%)	No. (%)		
Gender						
Male	7 (20)	14 (40)	13 (37.14)	1 (2.86)	0.004	0.999
Female	13 (20)	26 (40)	24 (36.92)	2 (3.08)		
Age						
20-29	6 (35.29)	8 (47.06)	3 (17.65)	-	15.288	0.018*
30-39	9 (22.5)	18 (45)	12 (30)	1 (2.5)		
40-49	5 (13.16)	12(31.58)	20 (52.63)	1 (2.63)		
50-60	-	2 (40)	2 (40)	1 (20)		
Marital status						
Unmarried	6 (19.35)	9 (29.03)	15 (48.39)	1 (3.23)	6.482	0.371
Married	13 (20.97)	28(45.16)	20 (32.26)	1 (1.61)		
Widow	1 (14.29)	3 (42.86)	2 (28.57)	1 (14.29)		
Education						
Literate	14 (17.5)	32 (40)	32 (40)	2 (2.5)	2.556	0.465
Illiterate	6 (30)	8 (40)	5 (25)	1 (5)		
Occupation						
Unemployed	5 (13.51)	13(35.14)	17 (45.95)	2 (5.41)	7.581	0.05
Employed	5 (15.15)	15(45.46)	12 (36.36)	1 (3.03)		
Self-employment	10 (33.33)	12 (40)	8 (26.67)	-		
Religion						
Hindu	12 (20)	24(40)	23 (38.33)	1 (1.67)	6.603	0.339
Buddhist	3 (25)	5 (41.67)	4 (33.33)	-		
Muslim	4 (17.39)	8 (34.78)	10 (43.48)	1 (4.35)		
Christian	1 (20)	2 (40)	1 (20)	1 (20)		
Type of family						
Nuclear	8 (17.39)	16(34.78)	20 (43.48)	2 (4.35)	2.352	0.502
Joint	12 (22.22)	24(44.44)	17 (31.48)	1 (1.85)		
Caregiver's relation with patient					14.649	0.023*
Parents (Father/Mother)	12 (27.27)	22 (50)	10 (22.73)	-		
Spouse	5 (13.16)	14(36.84)	18 (47.37)	1 (2.63)		
Children(Son/Daughter)	2 (20)	2 (20)	5 (50)	1 (10)		
Sibling	1(12.5)	2 (25)	4 (50)	1 (12.5)		

*Significant level at*p<0.05*

Table 2: Correlation between level of burden and depression among caregivers of patients with epilepsy

Characteristics	Mean	Standard deviation	Correlation	p-Value
Zarit Burden Interview	36.43	13.53	0.953	≤ 0.01
Hamilton depression scale	16.39	5.03		

Table 1 shows that age group of caregivers (*p*= 0.018) and caregivers' relationship with patients (*p*= 0.023) were significantly associated with the level of burden among caregivers of patients with epilepsy. However, gender, marital status, education, occupation, religion and type of family were not significantly associated with the level of burden among caregivers of patients with epilepsy.

Table 2 shows Pearson correlation analysis between level of burden and depression among caregivers of patients with epilepsy. The result suggests that there was statistically significant positive relationship on HAM-D vs ZBI (*p*≤ 0.01).

DISCUSSION:

In current study, findings showed majority (65%) are female which is not consistent with the study [10] of Kaduna, Nigeria which shows (53%) are female caregivers of patient with epilepsy. In this study majority (44%) are parent caregivers and (37%) are unemployed which is not consistent with the study [11] of China which shows (55%) of caregivers are parents and (51.4%) are unemployed. In this study, results showed that caregivers (42%) reported high mean burden scores on the ZBI which is not consistent with the study [10] of Kaduna, Nigeria which shows (51.9%) caregivers reported high burden scores on the ZBI. The findings of the study revealed (50%) caregivers reported moderate depression on the HAM-D which is not consistent with the study[13] of China which shows (33.59%) caregivers reported depression on the HAM-D.

In present study, the result showed that age group of caregivers (*p*= 0.018) and caregivers' relationship with patients (*p*= 0.023) were significantly associated with the level of burden among caregivers of patients with epilepsy which is consistent with study [14] of Assam, Inida which shows that relatives who care for persons with epilepsy have higher burden of care giving (*p*≤ 0.05). Findings suggest that older age careers have more burden of caregiving which might be because of additional burden of family member with chronic illness. This study also suggest that spouse, children and siblings have more burden as caregiving can create negative impact on caregiver's psychological health and affect daily work performance. Caring for relative with epilepsy on regular basis takes away their time for personal care leisure and other commitments besides eroding their physical and mental health. According to many studies conducted burden might be associated with severe level of stigma in our society, apprehensions of family members because of uncertainty about future seizure attacks, feelings of shame, guilt, fear, over concerns.

In our study, findings showed that there was statistically significant positive relationship on HAM-D vs ZBI (*p*≤ 0.01). It suggested that depression among caregivers of patient with epilepsy increases with increase in care giving burden which is consistent with the study [15] of Dehradun, India which shows statistically significant positive correlation between depression and caregiving burden among caregivers of patient with epilepsy (*p*≤ 0.01).

Strength of the study is that focus was on adult patients with as literature on adult patients is sparse. Limitation of the study is that this study is hospital based and findings of the study might not necessarily reflect the situation in the wider community. In future findings call for further investigation of caregiver burden and quality of life in epilepsy in broader socioeconomic settings and for their inclusion in the physicians' treatment plan and epilepsy care quality measures.

CONCLUSION:

The study concluded that caregivers of patient with epilepsy are experiencing high level of care giving burden which is again correlated to depression among caregivers. This study has

recognized caregivers as "co-client". The study also highlight the need for comprehensive care system including addressing caregivers' health which would help in better follow ups of patients at clinics and care giving as well.

CONFLICT OF INTEREST: None

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