ORIGINAL ARTICLE

CORRELATION OF CAREGIVERS' STRAIN WITH PATIENTS' DISABILITY IN STROKE

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Background: Stroke results in serious long-term disability in fifty percent of the survivors, making them dependent on others for activities of daily living. Our study aims to study the effect of this dependence on care-givers. Cross sectional study. **Methods:** It was a cross sectional study conducted at Combined Military Hospital Peshawar from September to November 2020. Self-administered questionnaires were used to interview 96 patients with stroke and their caregivers selected through convenience sampling technique. Barthel Index was used to measure disability among patients, whereas Modified Caregivers Strain Index (M-CSI) was used for the caregivers. An association between the two scores was analyzed through Pearson's coefficient of correlation (*r*) and linear regression. **Results:** Mean ages of the patients and their caregivers were 66.13±11.32 and 36.32±13.71 years respectively. Median score of Barthel index was 1.00 (interquartile range 0.00- 9.75). Mean M-CSI score was 17.31±5.04. There was significant negative correlation between Barthel Index and M-CSI (R=0.542, $p<0.001$). No significant association was found between duration of stroke and history of recurrent stroke with Barthel Index ($p=0.399$ and $p=0.527$ respectively). **Conclusion:** Greater the dependence of patients for activities of daily living on their caregivers, higher is the level of strain among the latter. There is dire requirement of social support and rehabilitation centers to address the physical and mental needs of both the patients and their care providers.

Keywords: Stroke; Caregivers; Disability

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INTRODUCTION

Primary prevention of stroke is to address the risk factors. Secondary prevention of recurrent stroke relies on the management of the mechanism responsible for the stroke.[1–3] About 16.9 million individuals suffer from stroke worldwide every year.[3] It is second leading cause of death globally, with fatality rate of 5.9 million per year and serious long-term disability in the fifty percent of survivors.[4,5] The incidence of stroke is increasing with every passing day because of the increasing life expectancy and high prevalence of diabetes mellitus, hypertension, heart failure and obesity in the general population.[6] One in every four person has overt stroke by the age of 80 years, and nearly everyone experiences a silent or covert stroke during his lifetime.[2] Béjot Y *et al*, in a study provided evidence that 88.1% of all stroke cases are attributed to one or more of the following 10 risk factors: hypertension; diabetes mellitus; smoking; physical built up; dietary factors; limited physical activity; excessive alcohol consumption; psychosocial factors; cardiac diseases; apolipoprotein B (ApoB) to ApoA1 ratio. Most of the risk factors listed above are modifiable. One of the major causes leading to 35 percent of cases of stroke is hypertension.[3]

Neurological, functional and cognitive disability is the most important manifestations of acute stroke, which may render a patient psychologically shattered and physically dependent on others. The calamitous and unpredictable events in life of patient due to stroke affect the physical, mental, psychological and social well-being of the patients as well as their caregivers.[7] Despite advancement in management protocols of stroke and the reduction in its post event effects, its impact on the life of survivors and their primary caregivers is devastating. Though many indices for activities of daily living (ADL) exist, Barthel Index has become the most widely used scale to measure the outcomes or disability and dependence of the stroke patients on others.[8] It is a 10 items scale, that helps to identify the level of dependence of the patient on others for their daily life activities. These items address a patient assistance or time required by patient in carrying out essential 10 tasks of day-to-day life. The items are summed to give a score ranging from 0 to 100. Higher the score of Barthel index, less dependent the patient is.

Similarly, a modified version of the Caregivers strain index CSI (M-CSI) is widely adapted to measure strain-a combination of stress and burden, in caregivers of patients with disability due to different long-term illnesses.[9] Modified Caregivers strain Index is a 13-questions scale used to screen for caregiver strain related to care provision to the patient. It covers aspects of the caregivers' life including physical health, socioeconomic variables, time demand, and work-related issues. Higher the score more is the strain on caregiver. The aim of this study is to quantify the impact of care giving for stroke patients and to see if this is related to patients' functional status/ ability to perform

independently ADLs. The results would help in raising awareness about indirect impact of stroke on close family members. Psychological help to the caregivers would improve QOL for them as well as stroke patients.

MATERIAL AND METHODS

This cross-sectional study was carried out at Combined Military Hospital, Peshawar, from September 2020 to November 2020. Sample size was calculated using Free Statistics Calculator version 4.0.[10] Minimum of 95 patients and an equal number of caregivers was the required sample size, using alpha 0.05, beta 0.01 and expected correlation coefficient (r) of 0.42.[11] All patients, irrespective of their gender, with history of stroke for at least 3 months and having some degree of physical disability as a consequence of stroke were included in the study. Patients with acute stroke (<3 months), transient ischemic attacks, neurological disorders, history of traumatic brain injury; space occupying lesion and brain surgery were excluded. Patients and their caregivers were selected as couples using convenience sampling technique. Informed verbal consent was taken before interviewing the patients and their caregivers. Patients were interviewed verbally using a questionnaire, comprising 2 sections. The first one covered the socio-demographic variables and information regarding the subtypes, duration and severity of stroke. The second part comprised Barthel index, a 10 items scale that measures degree of independence from any degree of physical or verbal help for whatever reason. Score of 0–20 indicated total dependency, 21–60 severe dependency, 61–90 moderate dependency and a score of 90–99 showed slight dependency of patient on others.[12]

For caregivers, demographic data was noted down and information pertaining to M-CSI was obtained in direct face to face interview. The responses of the participants were obtained by giving numeric score of 2 to response "Yes, on regular basis", 1 to "yes, sometimes" and 0 to "No", to all 13 questions of the index. All the responses of the care providers were added to get a score in a range of 0–26, where score of 0 represented no strain while 26 was considered maximum strain on the primary caregiver.[9] For data analysis, we categorized strain into four categories: score 0: no strain; 1–8: mild; 9–16: moderate and ≥17: severe strain on the care providers. Data was analyzed using SPSS version 20. Continuous variables with parametric distribution were described as mean ± standard deviation, whereas variables with non- parametric distribution were described as median and interquartile range. Pearson's coefficient of correlation (*r*) and linear regression analysis was used to determine the relationship between scores on Barthel Index and M-CSI. $p \leq 0.05$ was considered significant.

RESULTS

A total of 96 patients and an equal number of caregivers were included in this study. Their baseline characteristics are shown in Table-1. Median score on Barthel index was 1.00 (interquartile range 0.00–9.75). Mean MCSI score was 17.13±5.04. Proportions of patients with different grades of dependency and caregivers with different levels of strain are shown in Fig-1. The effects of different demographic factors on Barthel index and M-CSI are shown in Table-2. There was a significant negative correlation between Barthel Index and MCSI (r =-0.542, $p<0.001$) (Figure-2)

Table-1: Socio-demographic characteristics of stroke patients and their caregivers (n=96)

Parameter		Patients (n=96)	Caregivers (n=96)
Age		66.13± 11.32	36.32±13.71
Duration of stroke (months)		8.50 (3- 72)	-
Recurrent stroke		25 (26.04 %)	-
Gender	Male (%)	64 (66.67%)	58 (60.42%)
	Female (%)	32 (33.33%)	38 (39.59%)
Type of Stroke	Ischemic	73 (76.04%)	-
	Haemorrhagic	23 (23.96%)	-
Family structure	Joint	45 (46.87%)	-
	Nuclear	51 (53.12%)	-
Relation with patient	Spouse	-	16 (12.5%)
	First degree relative	-	12 (65.62%)
	Second degree relative	-	63 (6.25%)
	Others	-	06(15.62%)
Any change in occupation due to care giving duties	Yes	-	05 (5.20%)
	No	-	91 (94.79%)
Education Level	Uneducated	38 (39.58%)	28 (29.16%)
	Primary	9 (9.37%)	22 (22.91%)
	Middle	11 (11.45%)	05 (5.20%)
	Secondary	21 (21.87%)	17 (17.70%)
	Intermediate	10 (10.41%)	06 (6.25%)
	Higher	7 (7.29%)	18 (18.75%)
Per month income (in PKR)	< 20,000	-	43 (44.79%)
	>20,000 but < 50,000	-	37 (38.54%)
	>50,000	-	16 (16.67%)

Table-2: Median Barthel index score and Mean M-CSI in relation to different demographic factors.

Barthel Index in relation with different demographic factors			
Parameter		**Median barthel index score (Inter quartile range)**	***p*-Value**
Type of Stroke	Ischemic	10.00 (0.00-55.00)	0.008
	Haemorrhagic	0.00 (0.00-10.00)	
Recurrent Stroke	Yes	5.00 (0.00-30.00)	0.930
	No	5.00 (0.00-55.00)	
Duration of Stroke	< 6 months	0.00 (0.00-10.00)	0.000
	≥ 6 months	30.00 (1.00-63.00)	
Hypertension	Yes	5.00 (0.00-47.50)	0.097
	No	30.00 (5.00-55.00)	
Diabetes Mellitus	Yes	10.00 (0.00-51.25)	0.477
	No	5.00 (0.00-48.75)	
Antecedent Physical Condition	Active	10.00 (0.00-52.50)	0.248
	Limited activity or bed bound	0.00 (0.00-15.00)	
Physiotherapy Sessions	Yes	12.50 (0.00-53.75)	0.160
	No	0.00 (0.000-32.50)	
M-CSI in relation with different demographic factors			
Parameter		Mean M-CSI score ± SD	
Gender	Male	16.60±4.97	0.536
	Female	17.92±5.10	
Family Structure	Joint	17.45±5.03	0.572
	Nuclear	16.76±5.05	
Education	Uneducated	17.26±5.02	0.971
	Educated	16.79±5.17	
Relation with patient	Spouse or first degree relative	17.04±5.15	0.614
	Others	17.43±4.72	
Monthly Income	< 50,000 PKR	17.46±4.88	0.380
	≥ 50,000 PKR	15.44±5.63	

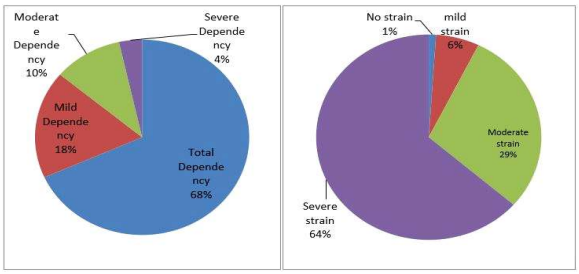

Figure-1: Proportions of patients with different grades of dependency and caregivers with different levels of strain

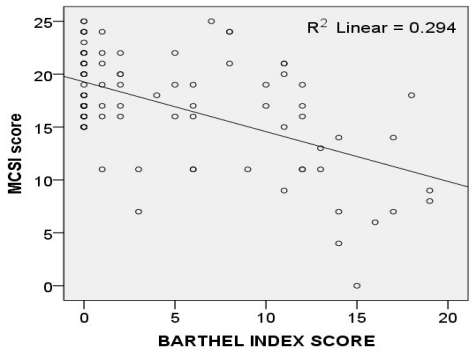

Figure-2: Correlation between Barthel index and MCSI score

DISCUSSION

Stroke burden has increased significantly in terms of incidence and disability resulting from stroke especially in developing countries, irrespective of gender.[13,14] In this study, data of 96 stroke patients and their caregivers was obtained to find the correlation between patients' disability and caregiver strain using Barthel index and MCSI respectively. The linear regression analysis revealed a strong correlation between Barthel index and modified care strain index. The level of dependency has direct relation with care giver strain. These findings were in congruent with a study conducted by Ogunlana *et al*, where poor quality of life of the caregivers was observed with high dependency of the patient on them.[15]

Our study showed that there was significant association of Barthel index with subtype of stroke (p=0.008) and duration of stroke (p=0.000). These results are similar to the findings of other studies. A study conducted in Malaysia showed that adjusted mean Barthel index score for haemorrhagic stroke were lower as compared to Ischemic stroke. Similarly, a rise in adjusted mean Barthel Index scores was noted in patients from the time of discharge up to 3-month post-discharge among acute

stroke patients.[16] No significant association was found between Barthel index and history of other co morbidities like hypertension, diabetes mellitus and recurrent stroke. These findings are in contrast to a study conducted by Cucchiara *et al*, it was seen that recurrent stroke, and some other serious adverse events were strongly associated with increased dependency on others.[17]

The median Barthel index value was 12.50 (interquartile range 0.00-53.75) in the stroke survivors who had physiotherapy sessions either at home or in any facility and0.00 (inter-quartile range 0.000–32.50) in those who didn't take such services (p=0.160). This gives a clue that physiotherapy doesn't have any role in decreasing the level of dependence of stroke patients on others. These finding are also favoured by other researches. Recent trials have not provided a clear benefit in improving post stroke outcomes in those who were given early rehabilitative therapy.[18] A multicentre, randomized controlled, endpoint blinded survey also does not support the use of aerobic bodyweight supported fitness training in stroke patients to improve activities of daily living.[19]

Out of 96 caregivers who took part in our study, 38 (39.59%) were female and 80 (83.33%) belonged to group with per month income <50,000 PKR. The mean MCSI in male and female caregivers was 16.60±4.97 and 17.92±5.101 (p=0.536). These statistics indicate strain is not dependent on gender of caregiver. These findings are in contradiction to other studies where higher level of strain was observed in female care givers.[20] Similarly the mean MCSI score in caregivers with per month income <50,000 PKR was 17.46±4.88 and 15.44±5.63 in group with monthly income of greater than 50,000 Pakistani Rupees (p=0.380). This is evident from these findings that no difference in strain is seen among the groups with different socioeconomic status. These findings were in contrast with that of other studies.[21.,22] It was observed in a survey conducted in South Korea, where poor quality of life (QOL) was seen in caregivers with poor health, lower income, and being a spouse. [20] Deterioration in mental health of care providers of stroke survivors is also alarming. The severity of anxiety and depression among caregivers has increased due to rise in caregivers' burden.[23]

Primary prevention of stroke is to address the risk factors. Secondary prevention of recurrent stroke relies on the management of the mechanism responsible for the stroke.[1] Decrease in incidence, mortality, morbidity and disability associated with stroke is noted in developed countries mostly due to improvement in primary and secondary preventive measures.[24] There is need to recognize and implement these measures in developing countries like Pakistan to improve post stroke outcomes.

A relevant limitation to our study was obtaining data from only one hospital. Also, post stroke outcomes on various aspects of life of survivors and their caregivers including physical, social, economic and psychological were not assessed separately. The score of Barthel index and MCSI were only obtained at the time of presentation that was at least 3 months after the stroke. We were not able to get these scores at the time patient had acute stroke. Also, we didn't follow these patients and their caregivers afterwards.

Researches on larger scale to validate these aspects are required. However, this study being the first study in this setup to describe the correlation between two important and commonly used scales. i.e., Barthel index and MCSI will provide guidelines for future studies and also will help to take appropriate steps to address different problems in various aspects of life faced by the patients and their caregivers.

CONCLUSION

The devastating effects of stroke affect the various aspects of life of not only stroke survivors but also their caregivers. Greater the level of dependence of stroke patients, greater is the strain faced by the care providers. Dedicated stroke units and rehabilitation centers to address the mental and physical needs of patients and their caregivers are the need of the hour. Also, it is desirable to recognize and implement the primary and secondary preventive measures in developing countries like Pakistan to improve post stroke outcomes.

AUTHORS' CONTRIBUTION

AS: Study design, drafting of manuscript, final approval, overall responsibility; KS: Data collection, drafting of manuscript, final approval, overall responsibility; ARA: Data analysis, critical revision, final approval, overall responsibility; KS: Interpretation of results; critical revision, final approval, overall responsibility; SHR: Study design, drafting of manuscript, final approval, overall responsibility.

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