

Disability and its Relationship with Caregiver Burden among Stroke Survivors: A Cross-Sectional Study

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Abstract

Background: Stroke is a chronic condition which leads to significant disability. In the developing countries like India such chronic conditions with disability are often kept to be treated in communities, which in turn puts significant stress on their caregivers ultimately leading to increase burden of caregiver. This increase in caregiver burden may further hamper the prognosis and rehabilitation of stroke patients.

Objective: Identifying and comparing the relation between the various level of disability and caregiver burden.

Study Design: Cross sectional study.

Method: 65 persons with stroke and their caregivers meeting the inclusive criteria's were enrolled.

Results: Pearson correlation was achieved between Modified Rankin Scale and Caregiver Burden Scale proving increase in caregiver burden with increase patient disability with 0.348 ($P < 0.01$), negative Pearson correlation between Modified Barthel Index and Caregiver Burden Scale proves decrease in independence level of patient increases caregiver burden with $-0.263(P < 0.05)$.

Conclusion: Caregiver burden of stroke survivor is correlated with disability of stroke patient. So education to caregiver may reduce burden which will may a key to improve rehabilitation.

Keywords: Stroke, stroke survivor, disability, caregiver burden.

Introduction

Stroke is a vascular origin neurological dysfunction affecting the cerebral function leading to focal and at times global damage with rapidly developing signs and symptoms lasting more than 24 hours resulting

in hemiparesis or leading to death due to an abnormal cerebral circulation.¹ Individuals are highly susceptible to disability and handicap subsequently after stroke.² Disability is defined as a complex phenomenon, where the problem is at the level of an individual's body and also a communal phenomenon according to International Classification of Functioning, Disability and Health (ICF). Disability is always an interaction between features of the individual with his/her environment which can be entirely internal or external to the person.³

Nearly 10%-30% of stroke survivor requires institutional care post discharge from hospital while the remnants decide to stay with their family and relatives. Life satisfaction of patients with stroke and their family members continues to get affected due to

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raise in physical, psychosocial, affective and cognitive disabilities of patient with increases in their survivors hip as development in medical science relatively increases their life span. Role and responsibilities of caregivers are extensive towards an individual affected by stroke as it frequently results in some disabilities for long term.^{4,5} Following stroke, more than 60% of survivors will need help of caregivers with at least in one of the activities of daily living (ADL).⁶

Caregivers are individuals who cater the disabled individuals who need assistance in ADL such as donning & doffing clothes, showering, cooking meals, transfers and perambulation with additional errands of administering medication, regularly monitoring pressure sores of bedridden patient.⁷ Availability of caregivers are of two types, primarily the informal caregivers who are unpaid individuals like parents and spouse family members and friends. The formal caregivers are helpers or paid workers allied with the social service or health care organizations.⁸ Study shows 74% of assistance was required with ADL among 3-month stroke survivors who received informal care from family or friends.⁹ A long term follow up study concluded 47% stroke patient received the assistance of a main caregiver. Patients with moderate or more severe disability were under supervision of caregiver at home.¹⁰

Functioning and quality of life (QOL) both significantly gets diminish in many recovering stroke patients which produces negative effects on caregivers. Emotional well-being, personal relationships, communal events and recreational time are adversely affected in most of the caregivers and it affects their psychological status and life causing in a harmful effect on the stroke survivors.¹¹ Caregivers with greater than $\frac{1}{3}$ rd of them linger to deliver extreme attention to the disabled while enduring from poor well-being themselves with most of them are ill-prepared for their role.¹²

Load on the family members and relatives raises physically and psychologically as majority of disabled individuals prefer to reside at their home with them rather than in rehabilitation centre. This occurrence of chronic disease significantly increases the informal care provided by family members as a result of site of the care shifting to their locality from rehabilitation centre which is evident in family reports.⁷ Caregivers make changes at their workplace, does schedule modifications, change their work-related travel or leave their jobs because of care giving distress. This in turn can lead to financial

burden increasing stress along with burden on caregivers making it demanding to address their necessities.¹³

Rehabilitation process of stroke patients is identified to get hampered because of its devastating and prolonged nature leading caregivers to undergo depression. Hence, it is vital to recognize the burden level of caregiver and its influencing components.¹⁴ Improving functional outcome in stroke rehabilitation, the role of family members gained lot of attention.¹⁵ Caregiver burden and patient functioning plays major role in any rehabilitation program.¹¹

Even though there may exist apparent relationship between disability and caregiver burden, the aim of the study was to specifically measure the effect size of the association of disability and caregiver burden among varying levels in stroke survivors.

Material and Method

This Cross-sectional study was commenced by using purposive sampling technique total of 65 individuals with stroke and their caretakers reaching the inclusive criteria's were enrolled from various rehabilitation centers and communities in Mangalore. All the patients and caregivers were explained about the study and an informed consent was obtained from them on voluntary basis. The sample of stroke patients consisted of 48 males and 17 females between the age group of 22 – 84 years. The caregiver consisted of 15 males and 50 females with age group of 18–82. The inclusive criterion for patients was medically stable patient with first stroke, patients who has an adult family member as a caregiver or professional caregiver and inclusive criterion for caregivers was age above 18 years. Demographic data along with other baseline were collected from patients as well as caregivers affecting caregiver burden.

Procedure: Disability of stroke patient was assessed with two scales namely modified Rankin Scale (mRS) for measuring global disability and modified Barthel Index (mBI) which measures different domains of disability. The mRS score ranged from 0 to 6, where 0 means no symptoms at all to 6 means extreme stage i.e. death.¹⁶ The mBI is a 5 point rating scale, with 10 domains which measures functional independence in personal care and mobility. It has total score of 100 with scores of 0–20 indicating total dependency, 21–60 severe dependency, 61–90 moderate dependency and 91–99 slight dependency.¹⁷

Caregiver Burden Scale (CBS) was used for measuring caregiver’s burden. The CBS measures the subjective impact on caregivers of patients with chronic diseases. It is a 22 item scale and the objective is to analyze the level of stress to which caregivers are subjected to. It is divided into four domains i.e. general strain, isolation, disappointment, emotional involvement and environment. The answers receive scores from 1 to 4 with 1 – not at all, 2 –seldom, 3 – sometimes, 4- often total score was recorded. The higher the score higher the degree of difficulty faced by the caregiver.¹⁸

Result

The data analysis were calculated by using the statistical software SPSS (version 16) for windows. In the stroke group, 36 were right hemiplegic and 29 were left hemiplegic. Pearson correlation between modified Rank in Scale among stroke survivor and Caregiver Burden Scale among caregivers was 0.348 (P<0.01) and between modified Barthel Index among stroke survivors and Caregiver Burden Scale among caregivers was -0.263(P<0.05).

Table 1. Pearson correlation between mRS and CBS

Correlations			
		MRS	CBS
MRS	Pearson Correlation	1	.348**
	Sig. (2-tailed)		.004
	N	65	65
CBS	Pearson Correlation	.348**	1
	Sig. (2-tailed)	.004	
	N	65	65

** . Correlation is significant at the 0.01 level (2-tailed).

Table 2. Pearson correlation between mBI and CBS

		MBI	CBS
MBI	Pearson Correlation	1	-.263*
	Sig. (2-tailed)		.034
	N	65	65
CBS	Pearson Correlation	-.263*	1
	Sig. (2-tailed)	.034	
	N	65	65

*. Correlation is significant at the 0.05 level (2-tailed).

Discussion

Stroke is the second largest cause of worldwide mortality which leaves at least 60% of its survivors with moderate to severe disability limiting their social

functioning.^{19,20} It is highly noticeable that at present people are alive for longer period of time with prolonged and frequently occurring devastating disorders. Greater demands on caregivers and patients can dramatically impact on role of caregiver. Caregivers with high burden level or who have unmet required needs tend to hamper their ability to function efficiently comprising their role as an ongoing support system for the affected individuals which emphasis the health experts to focus on caregivers. High degree of burden on caregiver has left patients with more unmet needs leaving home care support extremely vulnerable. Hence caregiver becomes a serious element of home care.²¹ Therefore the aim of the study was to find out the relationship between the disability and caregiver burden in stroke survivors.

Conclusion

The first objective of the study was to correlate patient disability and caregiver burden, where positive correlation between mRS and CBS concludes that caregiver burden of stroke survivor is correlated with disability of stroke patient which implies that as disability increases caregiver burden also increases but the correlation level was very low. There could be numerous possible reasons for this, mainly the caregiver in this study did not express it as a burden and rather it was the responsibility on their part to take care.

The second objective of the study was to correlate functional status of patient and caregiver burden, where negative correlation between mBI and CBS concludes that functional independence decreases caregiver burden increases. Hence we can conclude that education to caregiver can reduce burden compared to control group.

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