

Impact of Caregiver Strain on the Quality of Life of Stroke Patients

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Abstract: ***Background:** Stroke patients may remain physically or cognitively impaired. Caring for a family member takes time and can be burdensome, resulting in feelings of depression and stress. Hence from study we try to find out if there is a correlation between burden on the care taker and quality of life of the stroke patient. **Aim:** To study the impact of caregiver strain on the Quality Of Life of stroke patients. **Objectives:** To assess the quality of life in stroke patients, strain on the caregiver of the stroke patient and find the correlation of caregiver strain on the quality of life of stroke patients. **Outcome Measures:** Functional independence measure, Modified caregiver strain index, SF 36. **Methodology:** SF-36 was performed on the stroke patient (FIM 18-90) and modified caregiver strain index on the informal caregiver of the patient. **Results:** There is mild correlation between care giver strain and the quality of lives of stroke patients. **Conclusion:** This study found a mild correlation between caregiver strain and quality of life of stroke patients. A shift from patient-centered approach to a patient- and caregiver-centered approach will have better long-term outcomes.*

Keywords: stroke, caregiver, strain, quality of life

1. Introduction

Stroke or brain attack is the sudden loss of neurological function caused by an interruption of blood flow to the brain¹. Stroke is the second leading cause of death around the world and one of the main cause of years living with disability in adults.²⁻³ Stroke is a major disabling health problem in developing countries like India. Stroke burden in India has been rising in the last few decades, in contrast to developed countries where it has decreased. The average annual incidence rate of stroke in India currently is 145 per 100,000 populations, which is higher than the western nations. In India 10% to 15% of strokes occur in people aged below 40 years⁹. After stroke, physical impairments such as weakness, poor voluntary control, spasticity and loss of balance and coordination are common.⁵⁻⁶ These impairments cause limitations in mobility and upper limb activities, restricting the person with stroke from returning to his or her everyday activities⁷⁻⁸ and in turn affecting their quality of life.

Quality of Life (QOL) is a sense of total well being that encompasses both physical and psychological well being. Most stroke patients experience deterioration in the quality of life¹²

Most stroke survivors return to their own home after a hospital stay and from that time it is the caregiver who has to look after the patient. Caregivers of stroke patients often have to cope with patients' physical and cognitive impairments, communication and behavioral changes, and emotional problems. Some caregivers are able to cope well in this situation, others experience stress and depression. In the long term some are unable to continue looking after the patient.¹⁰⁻¹¹ Hence stroke can have an impact on the caregiver too.

As physiotherapists we generally tend to treat the motor and sensory deficits that accompany stroke. Assessing the QOL of the patients gives an insight regarding overall impairments. The burden of stroke might affect the patients' caregivers and their QOL. Mental health of the caregiver can affect the rehabilitation of patients as the caregiver is

constantly with the patient. Various studies have shown an impact on the health of the caretakers of stroke patients and about the burden on the caretakers.

In the study done by Willeke J Kruithof, Marcel WM Post and Johanna MA Visser-Meily -Measuring negative and positive care giving experiences: a psychometric analysis of the Caregiver Strain Index Expanded mentions as follows, 'Caring for a family member takes time and physical and emotional effort and can be burdensome, resulting in feelings of depression and a decreased quality of life.' The mental state of the caretaker may put an impact on the patient. Hence from study we try to find out if there is a correlation between burden on the care taker and quality of life of the stroke patient.

2. Methodology

The type of study used was Correlation study and convenient sampling method was used. Sample size of 60(30 care givers and 30 stroke patients). The subjects of the study were post stroke patients with GCS 14-15, FIM score between 18-90 and more than 4 weeks post stroke. The subjects with a FIM score above 90 and Mini Mental Scale score <23 were excluded from the study.

Outcome measures used were: 1) Functional Independence Measure (FIM)¹⁶ 2) SF-36 3) Modified Caregiver Strain Index¹⁷

Patients and their caregivers were explained the nature and purpose of the study. 40 stroke patients were screened and 30 were selected according to the inclusion criteria (FIM 18-90). Written consent of the patient and caregiver was taken. SF-36 was performed on the stroke patient and caregiver strain index on the informal caregiver (family member) of the patient.

3. Results and Analysis

The Quality Of Life of 30 stroke patients was assessed using SF-36 and caregiver strain of 30 caregivers was measured using Modified Caregiver Strain Index. The statistical

analysis of the data collected was carried out using Graph Pad prism7 and the data was further analyzed using the Pearson's correlation coefficient. Out of the total stroke patients 34% were in the age group of 61-70years, 30% (51-60 years),20%(41-50),10%(71-80),3%(21-30&31-40).40% of the stroke patients analyzed were females and 60% males.

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Characteristics	Patients
No. Of Males	18
No.Of Females	12
Age(Mean)	51
Sf 36-Physical Domain	34.3
1. Physical Function	26.5
2. Limitation Due To Physical Health	7.5
3. Pain	53.75
4. General Health	47.38
Sf-36 Mental Domain	36.4
5. Limitation Due To Emotional Problems	33.14
6. Vitality	36
7. Emotional Well Being	45.6
8. Social Functioning	30.9
Funtional Independence Measure	18-90
Caregivers	30
Males	6
Females	24
Age	23-78
Modified Caregiver Strain Index=	Mean=14.22

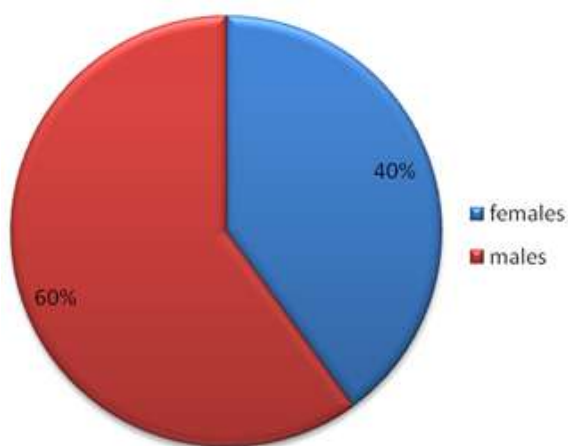
Mean Scores

MCSI	SF-36	PD	MD
14.22	32.2	34.3	36.4

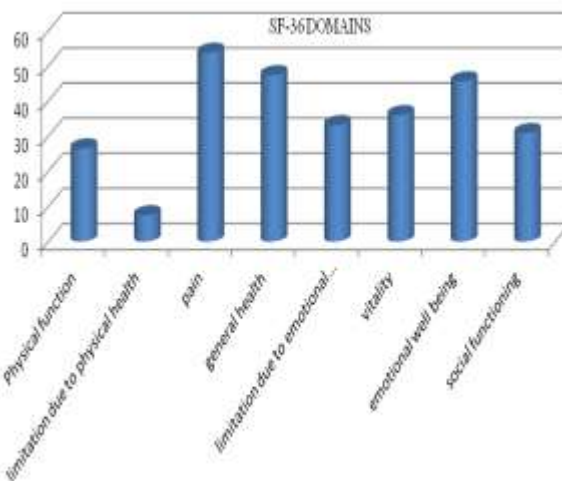
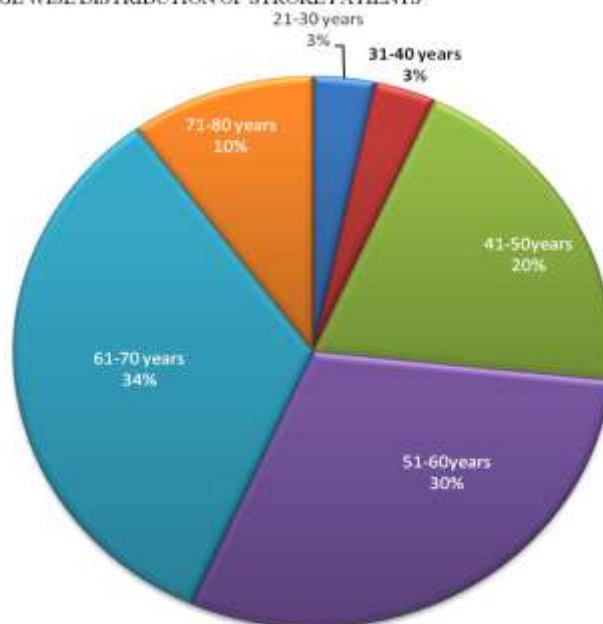
'R' Values

MSCI V/S SF-36	MSCI V/S PD	MSCI V/S MD
0.1213	0.1536	0.08717

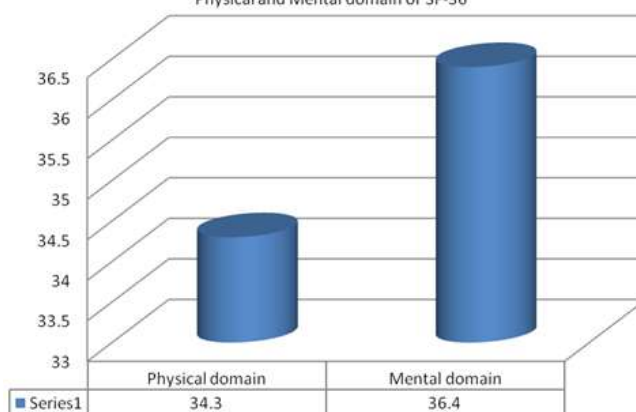
GENDERWISE % OF STROKE PATIENTS



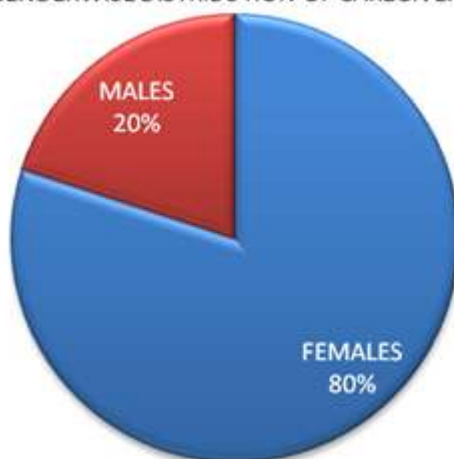
AGE WISE DISTRIBUTION OF STROKE PATIENTS



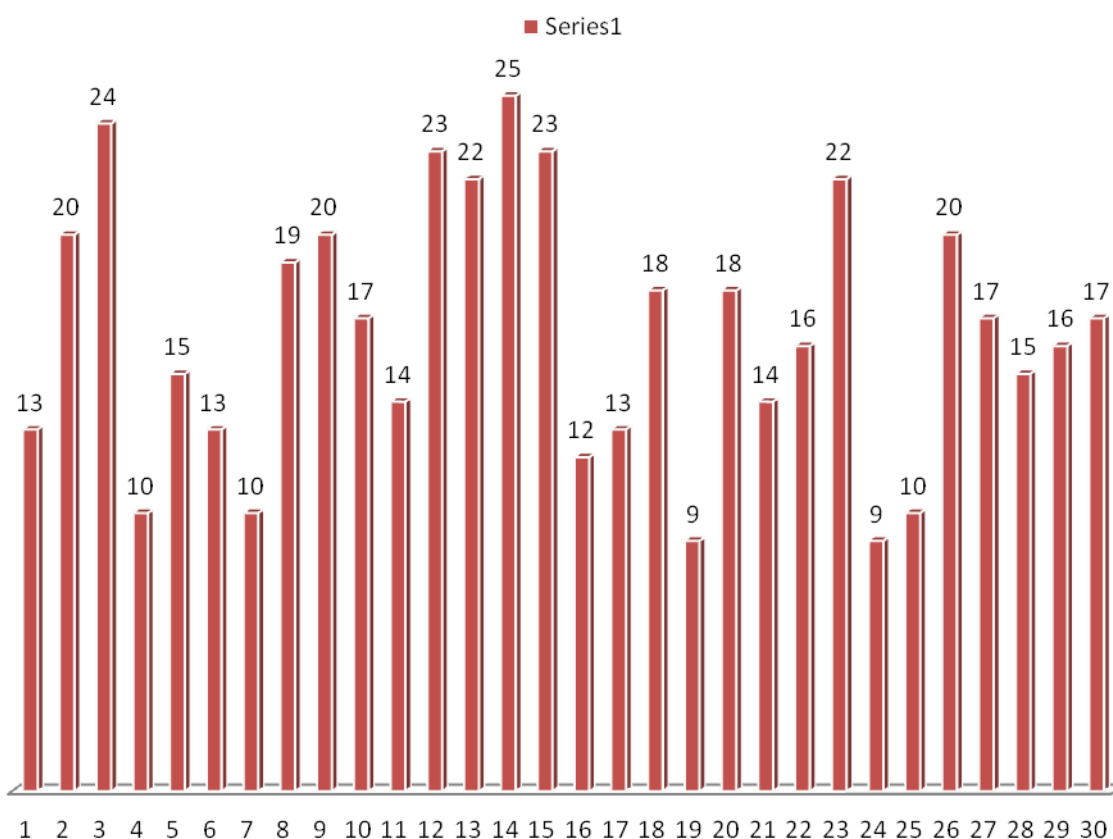
Physical and Mental domain of SF-36



GENDERWISE DISTRIBUTION OF CAREGIVERS



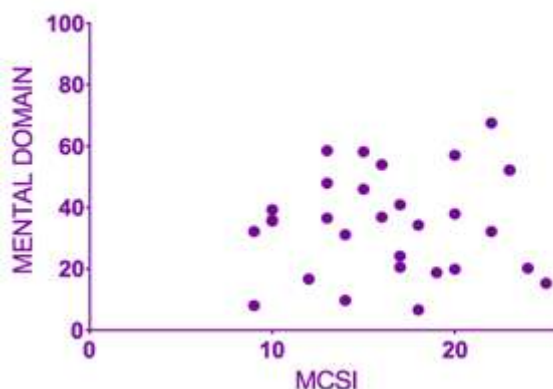
MODIFIED CAREGIVER STRAIN INDEX SCORES



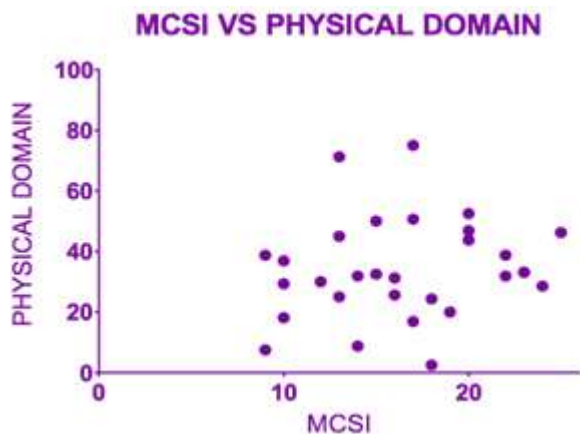
X axis: Serial number of caregivers
 Y axis: Caregiver Strain Index scores

r	0.1213
95% confidence interval	-0.2499 to 0.4614
R squared	0.01471
P value	
P (two-tailed)	0.5231
P value summary	ns
Significant? (alpha = 0.05)	No
Number of XY Pairs	30

MCSI VS MENTAL DOMAIN



r	0.08717
95% confidence interval	-0.282 to 0.4338
R squared	0.007598
P value	
P (two-tailed)	0.6469
P value summary	ns
Significant? (alpha = 0.05)	No
Number of XY Pairs	30



r	0.1536
95% confidence interval	-0.2188 to 0.4869
R squared	0.02359
P value	
P (two-tailed)	0.4178
P value summary	ns
Significant? (alpha =0.05)	No
Number of XY Pairs	30

4. Discussion

This study ‘IMPACT OF CAREGIVER STRAIN ON THE QUALITY OF LIFE OF STROKE PATIENTS’ was done to find a correlation between caregiver strain and the quality of life of the stroke patients. The quality of life of the stroke in patients was assessed using sf-36 questionnaire. Modified caregiver strain index was used to assess the caregiver strain.

The onset of disability in stroke is sudden and hence patients take time to cope with this new situation. Patients have to depend on their caregivers to perform ADLs and hence has a negative impact on the QOL of patients and caregivers

On analyzing the quality of life the following was observed: 1.limitations due to physical health (7.5%),social functioning (30.9%),physical function (26.5%) limitation due to emotional problems (33.14%),vitality (36%),emotional well being (45.6%),general health (47.38%),pain (53.75%).The section of ‘limitation due to physical health’ was most affected and that of pain was least affected. On comparing the physical and mental domain, the physical domain showed slight more affection than mental domain. Another study Quality of Life 4 Years after Stroke. The results showed that in spite of a good recovery in terms of discharge from the hospital, activities of daily living, and return to work, the quality of life of most patients (83%) had not been restored to the pre-stroke level. Deterioration among the several domains of life

ranged from 39% to 80%, the lowest being in the domain of activities at home and the highest in the domain of leisure time activities.

Berit et al in their study ‘Disablement and Quality of Life after Stroke’ mention that there was a correlation between changes in quality of life and ADL capacity. Thus, as a mean, quality of life deteriorated progressively with increasing degree of disablement.

Weakness due to spasticity, abnormal reflexes, altered coordination and motor programming, problems in speech, perception and coordination, altered emotional status and disturbed bowel and bladder functions are some of the problems faced by stroke patients.¹ Thus stroke patients need constant assistance and care. Hence the physical domain showed more affection than mental domain.

Care giving is an immediate aftermath due to stroke. The caregiver strain was measured using the modified caregiver strain index.CSI showed that almost 30%of the subjects had severe caregiver strain while remaining subjects had moderate caregiver stain.90% of the caregivers were females. Majority of the caregivers had financial burden due to the additional expenses or due to the stroke patient being the only earning member. Sleep getting disturbed ,changes in personal plans of caregivers and feelings of being totally overwhelmed regarding the future were seen in almost all of the caregivers.The factors that cause burden to the caregiver depends on contextual factors e.g. age, finances and health, characteristics of affected person and characteristics of the caregiver.Craig S. Anderson in their study concluded that the high level of emotional distress among caregivers of stroke patients suggests that many caregivers have unmet needs. Community services need to focus attention on the neuropsychological aspects of stroke patients and the social functioning of caregivers who support them.

The final statistical analysis showed mild correlation between caregiver strain and the quality of life of stroke patients. As most of the caregivers are females they have feelings of increased responsibilities and take it as a part of their daily routine. The realizations of the mental, physical and emotional changes that take place in the caregivers are often neglected. Hence they open up slowly regarding feelings of strain.

Anxiety and depression are common in stroke patients and their caregivers and determine care giving burden. Studies show that social services support or interventions aimed at the emotional support of caregivers have little effect on reducing this burden. However, “hands on” training in the day to day management of stroke patients was associated with lower anxiety and burden of care levels¹⁴ To improve the caregiver situation, individual patient personality characteristics, like extroversion, feeling of quality of life, and progression of the disease, must be considered¹³.

Care giving is a complex and multidimensional activity and hence regular counseling given to the caregivers will improve their emotional and mental health which will aid in early recovery of the patient as well.Care givers can also be motivated to follow a hobby for sometime in the day which

can help them to improve their emotional and mental well being.

Caregivers with high perceived self-efficacy, satisfied with social support, and frequently using the coping strategy confronting, experience less strain, higher mental well-being and greater vitality.¹⁵

The limitations encountered during the study were rapport building within a short period of time with the caregiver was difficult. Social desirability bias, in which participants tend to answer questions in a manner that will be regarded favorably by others, could have occurred. However, most questionnaires were self-administered. Considering the frailty and advanced age of this population, QOL measures should be evaluated in terms of their simplicity and their capacity to differentiate the effects of age from those of illness. For example, in the functional domain it is sometimes difficult to differentiate physical disabilities resulting from stroke from dysfunctions related to the normal aging processes.

This suggests that a shift in rehabilitation philosophy from a patient-centered approach to a patient- and caregiver-centered approach, which empowers caregivers, may have better long-term outcomes.

Thus, from the study it has been seen that disability of the patients following stroke has a negative impact on their quality of life and this leads to major strain on the caregivers. It is thus important to provide caregivers with emotional support and coping strategies to minimize the detrimental effects of care giving as caregivers play a keyrole in stroke recovery process.

5. Conclusion

This study found a mild correlation between caregiver strain and quality of life of stroke patients. There is a weak correlation between caregiver strain and physical domain of SF-36. Thus care givers do undergo considerable amount of strain. This strain must be addressed appropriately by giving regular counseling sessions to the caregivers and training effective ways for handling the patient. Thus a shift from patient-centered approach to a patient- and caregiver-centered approach will empower caregivers and may have better long-term outcomes.

6. Future Scope

A larger sample size can be used (30 subjects in each group used in this study). Building a rapport within a short period of time with the caregiver was difficult. Social desirability bias, in which participants tend to answer questions in a manner that will be regarded favorably by others, could have occurred. However, most questionnaires were self-administered. Rapport building will help to overcome this problem

Considering the frailty and advanced age of this population, QL measures should be evaluated in terms of their simplicity and their capacity to differentiate the effects of age from those of illness. For example, in the functional domain it is

sometimes difficult to differentiate physical disabilities resulting from stroke from dysfunctions related to the normal ageing processes.

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