



Employment status, social function decline and caregiver burden among stroke survivors. A South Indian study

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ABSTRACT

Stroke leaves at least 60% of the survivors with moderate to severe disability limiting their employment status and social functioning leading to high levels of caregiver burden.

Aim: We sought to study the employment status and level of change of social functioning of stroke survivors and their principal caregiver and correlate it with severity of stroke, functional disability, and anxiety and depression scores.

Methods: One hundred and fifty stroke survivors and principal caregivers (3 months–2 years post-stroke) were recruited for the study. The employment status pre- and post-stroke was assessed. The social function of the patient and caregiver was analyzed using a 6 item social function scale developed for the study, encompassing culturally relevant questions. A 20 point scale adapted from Burden assessment schedule was used to assess the caregiver burden.

Results: Mean age of the study group was 54.37 ± 12.072 (range 22–75 years), with 116 males and 34 females. Spouse was the principal caregiver for 142/150 patients (94.6%). In the stroke survivors, compared to the pre-stroke employment status of 62.7%, only 20.7% were employed post-stroke with half having change of job. But the employment status of caregiver was not reduced post-stroke (34.7% vs 33.3%). Employment loss in stroke survivors had a statistically significant association with severity of functional disability, male gender and presence of limb weakness (*p* values 0.037, 0.0001 and 0.043 respectively). There was an overall decline in social functions among the 6 parameters assessed in both the stroke survivors and caregivers. Of the caregiver burden, financial burden was more among female and older caregivers. The functional status and motor weakness of the stroke survivors did not tend to worsen the overall caregiver burden.

Conclusions: Loss of occupation among stroke survivors is high. The decline in social function among stroke survivors and caregivers was significant. Even though functional disability contributed to employment loss and social function decline among stroke survivors, it did not have a significant impact on caregiver burden.

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1. Introduction

Ischemic stroke, the second largest cause of mortality worldwide leaves at least 60% of its survivors with moderate to severe disability, limiting their employment status and social functioning [1,2]. A population based study from our region showed that 57.7% of urban and 56.8% of rural stroke survivors are left with moderate to severe disability [5]. Even though incidence of stroke and related deaths has declined in high income countries, the incidence has doubled in medium and low income countries in the last decade. With increasing life expectancy of the population and high prevalence of life style diseases, low and middle income countries are facing great social and financial challenges in coping with disabled stroke survivors [3]. A

recent population based study on self reported stroke and disability from India, China and Latin America [4] reported that even though self reported stroke rate was low in rural and urban India (1.1% and 1.9% respectively), proportion of stroke survivors needing varied care was high in rural India (73%).

In developing countries like India, hospital and community based rehabilitation facilities are limited. This puts the burden of caring stroke survivors mainly upon the family leading to high levels of caregiver burden. With spouse being the major caregiver, their employment and social function also suffers on the long run. South London Stroke Registry reported that even though functional recovery was associated with return to paid employment post-stroke, large proportion of patients with excellent functional outcome had not resumed work [6]. There is scant data about factors contributing to loss of employment of patients with mild to moderate strokes and their caregivers.

Caregiver burden related to chronic illnesses like stroke and cancer is an area receiving great deal of attention in developed countries.

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A review on long term impact of stroke on its survivors and caregivers found that social and emotional consequences represent the single largest problem area among stroke survivors and caregivers, seen in around 39% [7]. Even though a few Indian authors have studied caregiver burden in stroke and their predictors [8–10], its impact on social functioning, integration and employment status is not well understood. Even the caregivers of minor stroke survivors with little or no disability are found to have reduced QOL measures at 1 year post-stroke, with increase in depression and decline in marital function [11].

2. Aims

We sought to study employment status and level of change of social functioning of stroke survivors and their principal caregiver and correlate it with severity of stroke, functional disability, and anxiety and depression scores. Also we assessed caregiver burden on 3 parameters – namely financial situation, family relationships, and physical and mental stress.

3. Materials and methods

This study was conducted by Comprehensive Stroke Care Centre, Department of Neurology, Sree Chitra Tirunal Institute for Medical Sciences and Technology, a tertiary care center for Neurological disorders in Trivandrum, South India. 150 stroke survivors and caregivers (3 months–2 years post-stroke) were recruited for the study from stroke outpatient clinic during their follow-up. Study period was from January 2011 to June 2012. Study was approved by institutional ethics committee. After informed consent was obtained, demographic profile, clinical details of stroke and risk factor status were collected by interview and examination by the stroke neurologists. Stroke severity was assessed using National Institute of Health Stroke severity scale (NIHSS) and scores 0–3, 4–15 and >15 were classified as mild, moderate and severe strokes respectively [12]. Stroke disability was assessed using modified Rankin scale (mRS) where ≤ 2 was considered as good outcome, and 3, 4 and 5 as poor outcome [13]. In addition, details of employment of patient and caregiver pre- and post-stroke were collected by a medical social worker, including any change in job. Social function status of the patient and caregiver was assessed using a set of 6 questions which was culturally relevant to Indian context. They were visits to religious institutions, attending marriage functions, attending other social gatherings, participation in cultural/entertainment activities, visits to relative's places and trips for shopping. Caregiver burden was assessed using a 20 point questionnaire assessing 3 different parameters – financial situation, physical and mental stress and family and social relationships. The scale is an adaptation of Burden assessment schedule which is a 40 point questionnaire for assessing caregiver burden, validated in Indian population [8]. All the patients and their principal caregivers were screened for anxiety and depression using hospital anxiety and depression scale (HADS) and each subset score ≥ 11 was considered as significant [14].

3.1. Statistical analysis

SPSS version 16 software (SPSS Inc., Illinois, Chicago) was used for statistical analysis. Descriptive data were expressed in means and percentages. Chi square test and Fisher exact test were used to assess correlation between employment loss and social function decline of patient and caregiver with stroke severity, disability, neurological deficits, risk factor status and anxiety and depression. In the caregiver burden scale, we used univariate analysis to test the association of each question with demographic factors, stroke disability and anxiety and depression scores. *p* values less than 0.05 were taken as statistically significant.

4. Results

Mean age of the study group was 54.37 ± 12.072 (range 22–75 years), with 116 males and 34 females (7.7:2.3). Majority of patients in the study group (64.7%) were above 50 years of age. Spouse was the principal caregiver for 142/150 patients (94.6%). The mean NIHSS was 3.17 (range, 0–18) and mRS was 2.21 (0–5). The baseline characteristics are given in Table 1.

4.1. Employment status of patient and caregiver

Over 60% of the stroke survivors and 30% of caregivers were in paid employment before the illness. Employment status and change post-stroke are given in Table 2.

Among the patients who were employed post-stroke, 51.3% had a change of job whereas 48.7% could retain the same job they were doing before the illness. Employment loss in stroke survivors had a statistically significant association with severity of functional disability (mRS), male gender and presence of limb weakness (*p* values 0.037, 0.0001 and 0.043 respectively), while that of in caregivers had an association with high anxiety scores on HADS (*p* value 0.047). Severity of stroke – mild versus moderate, higher depression scores on HADS or speech disturbances – had no statistically significant correlation with unemployment status of stroke survivor or caregiver.

4.2. Social function decline

Among stroke survivors, there was an overall decline in social functions among the 6 parameters assessed – that is visits to religious places, attending marriage functions, other social gatherings, participation in cultural activities, visits to relative's places and trips for shopping. It was found to have a positive correlation with severity of functional deficit, male gender and presence of limb weakness in univariate analysis. Among caregivers, there was an increase in frequency of visits to religious places which had a significant association with high anxiety scores on HADS. Other social functions showed a trend for decline in caregivers especially in men. There was no statistically significant association between severity of stroke – NIHSS, type of stroke – ischemic versus hemorrhagic, presence or absence of atrial fibrillation, current tobacco use, current alcohol use and the decline of measured 6 parameters of social function. The correlations with decline of social function of stroke patient and caregiver are given in Tables 3 and 4 respectively.

Table 1
Baseline characteristics.

| | Number (N = 150) | Percentage |
|-----------------------------|---------------------------------|------------|
| Mean age | 54.37 ± 12.07 years | |
| Gender | 116 male:34 female | |
| Marital status – married | 142 | 94.6% |
| Stroke severity – NIHSS | | |
| Mild 0–3 | 104 | 69.3 |
| Moderate 4–15 | 43 | 28.7 |
| Severe >15 | 3 | 2 |
| Functional disability – mRS | | |
| Good 0, 1, 2 | 88 | 58.7 |
| Poor 3, 4, 5 | 62 | 41.3 |
| Risk factor profile | | |
| Hypertension | 108 | 72 |
| Diabetes | 70 | 46.7 |
| Hyperlipidemia | 72 | 48 |
| Atrial fibrillation | 3 | 2 |
| Prior stroke | 8 | 5.6 |
| HADS anxiety > 11 | 36 (mean anxiety score 8.07) | 24 |
| HADS depression > 11 | 37 (mean depression score 8.07) | 24.7 |

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