

Community-based longitudinal follow-up of Stroke patients discharged from a tertiary care center in Central India

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ABSTRACT

Context: Stroke is a condition that may affect the functionality of a person to a significant degree; however, there is very little data available that speaks about the objective state of a patient from a revalidated scale after the post-stroke event. **Aims:** To fill the knowledge gap and generate first-hand evidence about the post-stroke events in the community. To study post-stroke well-being of patients discharged from health facility and assess them longitudinally by Relevant Physical Examination, National Institute of Health stroke scale, and Modified Rankin Scale. **Methods and Materials:** Forty patients who suffered from first episode of stroke were followed in their home longitudinally by Relevant Physical Examination, National Institute of Health (NIH) stroke scale and Modified Rankin Scale. Patients under study were first visited after 2 months of discharge from the hospital set up after which two more follow-up visits were conducted at 2 months interval each. **Results:** There was an improvement in muscle power, sensation in the upper and lower limb, gait, and posture as well as language and vision in the patients in three subsequent visits. There was no significant difference in the fine movements of the patients. There was a gradual improvement in NIH score and there was a dominant presence of moderate-severe disability among the patients. **Conclusions:** Quantitative scales largely showed on a primary basis that on the physical dimension of the disease, the effects of Stroke were affecting the functioning of the body at optimum capacity and harmony.

Keywords: Disability, follow-up, modified Rankin scale, National Institute of Health stroke scale (NIHSS), Stroke

Introduction

According to World Health Organization, the clinical syndrome of “Stroke” can be defined as “rapidly developing clinical signs of focal (or global) disturbance of cerebral function with symptoms lasting 24 h or longer or leading to death, with no

apparent cause other than vascular origin.”^[1,2] According to recent population based studies in India, the incidence rate of Stroke is 119–145/100,000 while the crude prevalence rate varied from 257 to 471/1,00,000.^[3–6] The national death rate because of Stroke in 2016 was reported to be as high as 53/1,00,000.^[7] Consistent with recent population based studies, 55–70% of Stroke survivors became fully independent by 1 year and 7–15.7% remained completely disabled.^[8] The global burden of disease study projects that overall casualties from Stroke in India will exceed established market economies by 2020.^[9]

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With increase in the life expectancy, India will face significant socioeconomic burden to meet the costs of rehabilitation of Stroke survivors. Post-stroke consequences manifest in various forms like weakness or paralysis, difficulty in coordination, difficulty in using language (aphasia and dysarthria), bodily neglect or inattention, cognition issues, etc., Patients who suffered a stroke episode may experience trouble in performing “activities of daily living” (ADLs) like feeding, using the toilet, bathing, grooming and routine activities like mobility and talking, also “instrumental activities of daily living” (IADLs) like preparing food, driving which they usually performed normally earlier. Some limitations manifest right after Stroke while others become evident in time.^[10]

Neither mortality rates nor hospital discharge rates accurately reflect the extent of disability among stroke survivors, which is principally borne by patients and their families.^[11] As Stroke is chronic disabling condition, measures of function are appropriate for assessment of outcome. Functional assessment scales can give a numerical outcome to various abstract concepts like disability and hence they can be easily used to objectively quantify the deficits and track change over a period of time.

The National Institute of Health Stroke Scale (NIHSS) standardizes and quantifies the basic neurological examination, paying special attention to the aspects most relevant to Stroke. NIHSS scores are reliable across observers, and this has been demonstrated both in cohorts of neurology-trained and non-neurologist raters.^[12,13] The Modified Rankin Scale (MRS) is an ordinal hierarchical scale that describes disability with a focus on mobility.

The current study was conducted with the rationale that Stroke is a condition that may certainly affect the functionality of a person to a significant scale, however there is very few data available which speaks about the objective state of a patient from revalidated scale after post-stroke event. Hence this study is supposed to fill that knowledge gap and generate first-hand evidence about the post stroke events in the community. These patients are either missed or get unnoticed by our health system because our traditional model of healthcare does not have any provision for follow-up of these patients in the community.

Subjects and Methods

The community-based longitudinal follow-up study was conducted in Bhopal city for a period of one year from 1st October 2014 to 30th September 2015. Inclusion criteria were patients who suffered from their first stroke episode, who were residents of Bhopal and were admitted in a tertiary care center in Bhopal, a city in Madhya Pradesh, Central India. Their sociodemographic information was collected at the time of enrolment.

The current study was planned with the purview of taking the perceptions along with experiences of patients requiring the

sampling design to have a purposeful sampling strategy. As it was not possible to ensure the randomization of the participants in the study, there is no generalized formula to estimate the sample size in such settings hence it was decided to conduct 120 observations of 40 patients with three visits for each patient.

Patients under study were first visited after 2 months of discharge from the hospital set up. After first visit, two more follow-up visits were conducted at 2 months interval each. In this way total three visits per patient were conducted.

Data were collected using a semi-structured pre-tested proforma to know the sociodemographic profile of subjects, to assess neurological impairment through relevant physical examination, NIHSS (National Institute of Health Stroke Scale), and MRS (Modified Rankin Scale).

Modified BG Prasad Classification was used to determine the socioeconomic status of the participants. Physical examination included assessment of gait and posture by Romberg’s test, Tandem walking, Finger nose test, Finger to finger test and Dysidiadochokinesia; assessment of language and vision by looking for aphasia, dysarthria, visual acuity and eye movements; assessment of power, fine movements and sensations.

Ethical approval from the Ethical committee Gandhi Medical College Bhopal was obtained, and informed consent was taken from all participants.

Data collected during the study period was entered in Microsoft Office Excel 2007 and was analyzed using Microsoft Office Excel 2007, Epi info-7 and GraphPad online software in the open domain. Relevant tables and diagrams were formulated using Epi info-7 and MS Excel 2007. As the sample size was small it became necessary to test the normality of the data (NIH stroke scale values of first, second and third visit) so that appropriate statistical tests can be applied. For this purpose, Kolmogorov–Smirnov test and Shapiro–Wilks test were applied.

Results

This study includes 108 observations among 40 patients, (as eight patients died in between; four died before their second visit and four died before completion of the third visit, thus total 108 observations were made) who were followed for the duration of 6 months from the date of discharge from the tertiary care center. For each participant three follow-up visits were made with 2 months interval between each visit.

The study population mostly belonged to older age group of people with mean age of 63.28 years (SD ± 10.08). There were 28 males and 12 females in the study cohort. Most of the subjects were illiterate, majority of these were housewives as nine out of 12 of them did not go to school. Thirteen out of 40 total subjects were educated up to primary or middle school. Thirty four out of 40 post-stroke patients belonged to socioeconomic

status class III and class IV, that is, the majority of the patients were from lower social class. [Table 1]

Majority of the male patients under study were involved in smoking, alcohol addiction, and tobacco consumption while most females (8 out of 12) under study only used to consume tobacco (smokeless), none of them were found to have smoking or alcohol addiction.

Physical examination analysis was applied to a sub-group of 32 patients as 8 patients succumbed to mortality either between first and second or second and third visit. Hence all the three scores could be obtained only for 32 patients, in this way total 96 observations in three visits were made.

As many as eight stroke patients succumbed to death during follow-up. [Table 2] The cumulative survival analysis shows the

cumulative proportion surviving at the time of an event where event is defined as death.

Table 3 shows that there is a significant difference ($P < 0.005$) and improvement in muscle power, sensation in the upper and lower limb, gait and posture as well as language and vision in the groups in three subsequent visits. However, there is no significant difference ($P = 0.368$) in fine movements of the group.

Every patient was followed up in the community with the aid of NIHSS three times. This analysis was applied to a sub-cohort of 32 patients as eight patients either succumbed to mortality in between first and second or second and third visit. Hence all the three NIH assessment scores could be obtained only for 32 patients. Table 4 shows that there is an improvement in NIHSS scores in three subsequent visits.

The profile plot [Figure 1] shows an easy understanding of tabular results depicting there is a gradual decrease (improvement) in NIH score during three visits. Stroke survivors at 6 months post-discharge to home setting from health facility were in mild to moderate stage in terms of severity of Stroke.

Table 5 shows a median score achieved in all three visits as 4.00 which shows a dominant presence of moderate severe disability among the group. However, the 3rd quartile value during the first visit to third visit decreased from 5 to 4 (from severe disability to moderate severe disability) and 1st quartile value decreased from 4 to 3 (from moderate severe disability to moderate disability).

Table 6 compares the mean ranks between the related groups. The mean value of MRS score for the first group (MRSf) was found to be 2.15, for the second group (MRSs) it was 2.10 whereas for the third group (MRSt) it was 1.75. This table provides the test statistic Chi-square (χ^2) as 7.60, degrees of freedom (df) as 2, and the P value was found to be 0.022 ($P < 0.05$). Hence it was observed that there is an overall statistically significant difference between the mean ranks of the related groups.

Friedman test is an ominous test which tells us whether there are overall differences but does not pinpoint which groups differ from each other, to do this we need to run post-hoc test. Wilcoxon Signed Ranks Test was used for comparing the scores of three visits with each other to detect any difference. The median levels for MRSf and MRSs were 4 (4 to 5) and 4 (4 to 4), respectively. There was no significant difference between MRSs and MRSf ($Z = -0.471, P = 0.637$). This shows that on a non-parametric scale there was no significant difference or improvement in disability status between 1st and 2nd follow-up. The median levels for MRSt and MRSs were 4 (3 to 4) and 4 (4 to 4), respectively. Wilcoxon signed-rank test showed a statically significant change between these two groups. ($Z = -3.162, P = 0.002$) It can be inferred that on a non-parametric scale there was a significant difference and steady improvement in the disability score from second visit to third visit.

Table 1: Baseline characteristics of enrolled patients

Characteristic	Number	Percentage
Gender		
Male	28	70
Female	12	30
Marital status		
Married	30	75
Widow/widower	10	25
Education		
Illiterate	15	37.50
Upto middle school	13	32.50
High school and above	12	30
Occupation		
Government employee	2	5
Private employee	6	15
Farmer	2	5
Self employed	10	25
Retired	8	20
Housewife	12	30
Socioeconomic status		
Class I	0	0
Class II	5	12.5
Class III	17	42.5
Class IV	17	42.5
Class V	1	2.5
Type of Family		
Nuclear	22	55
Joint	18	45
Dietary preference		
Predominantly vegetarian	28	70
Predominantly non-vegetarian	12	30
Associated co-morbidities		
Hypertension	22	55
Diabetes mellitus	8	20
Cardiac diseases	6	15
Any other disease	9	22.5
Substance abuse		
Smoking	16	40
Drinking alcohol	10	25
Tobacco consumption	30	75

Table 2: Survival Table

Patient ID	Time of mortality (Weeks)	Status	Cumulative Proportion Surviving at the Time		Number of Cumulative Events	Number of Remaining Cases
			Estimate	Standard Error		
9	2	Dead	0.975	0.025	1	39
14	5	Dead	0.965	0.034	2	38
17	5	Dead	0.925	0.042	3	37
19	6	Dead	0.900	0.047	4	36
29	9	Dead	0.875	0.052	5	35
34	11	Dead	0.850	0.056	6	34
37	12	Dead	0.825	0.060	7	33
39	14	Dead	0.800	0.063	8	32
1	16	Survived	.	.	8	31
2	16	Survived	.	.	8	30
3	16	Survived	.	.	8	29
4	16	Survived	.	.	8	28
5	16	Survived	.	.	8	27
6	16	Survived	.	.	8	26
7	16	Survived	.	.	8	25
8	16	Survived	.	.	8	24
10	16	Survived	.	.	8	23
11	16	Survived	.	.	8	22
12	16	Survived	.	.	8	21
13	16	Survived	.	.	8	20
15	16	Survived	.	.	8	19
16	16	Survived	.	.	8	18
18	16	Survived	.	.	8	17
20	16	Survived	.	.	8	16
21	16	Survived	.	.	8	15
22	16	Survived	.	.	8	14
23	16	Survived	.	.	8	13
24	16	Survived	.	.	8	12
25	16	Survived	.	.	8	11
26	16	Survived	.	.	8	10
27	16	Survived	.	.	8	9
28	16	Survived	.	.	8	8
30	16	Survived	.	.	8	7
31	16	Survived	.	.	8	6
32	16	Survived	.	.	8	5
33	16	Survived	.	.	8	4
35	16	Survived	.	.	8	3
36	16	Survived	.	.	8	2
38	16	Survived	.	.	8	1
40	16	Survived	.	.	8	0

Discussion

In the present study, patients were first visited after 2 months of discharge from the hospital set up. Eight patients died during the study period (four died before their second visit and four died before completion of the third visit), so out of 40 patients, 32 survived at sixth months, that is, till the completion of third visit. After 6 months, 80% of the 60-day stroke survivors (first visit at the completion of two months from the date of discharge) were still alive. Non-adherence to current regimen, lack of rehabilitation at home setting and shifting treatment to other remedies or practicing existing culture-specific beliefs about stroke also affected the survival and outcome of the diseased.^[14]

In a study by Liu X *et al.*, it was found that the overall survival rate was 86.4% at the end of the 1-year follow-up. Advanced age, hypertension, diabetes mellitus (DM), cardiovascular diseases, and cigarette smoking were associated with an increased risk of death 1 year after stroke.^[15] The important influence of cardiovascular disease on the first-year survival rate emphasizes the significance of acute stroke management and control of hypertension.

In the current study, we found that patients suffered from stroke attack mostly belonged to older age group of people with mean age of 63.28 years (SD ± 10.08). This data shows similarities with the study of Pandian *et al.*, 2013, conducted in a tertiary

Table 3: Analysis of physical examination in three subsequent visits

Physical examination	Visit number	Quartile			Mean rank	Test statistics
		First	Median	Third		
Analysis of muscle power in three subsequent visits:	First visit	24.00	33.00	38.00	1.34	Chi square=22.441 Df*=2 P=0.000
	Second visit	31.25	37.00	40.00	2.34	
	Third visit	31.25	37.00	40.00	2.31	
Analysis of sensation of upper and lower limb in three subsequent visits	First visit	0.00	0.00	1.75	1.59	Chi-Square=24.571 Df=2 P=0.000
	Second Visit	0.00	2.00	2.00	2.16	
	Third visit	0.00	2.00	2.00	2.25	
Analysis of fine movements of hand in three subsequent visits	First visit	0.00	0.00	1.00	2.03	Chi-Square=2.000 Df=2 P=0.368
	Second Visit	0.00	0.00	1.00	1.94	
	Third visit	0.00	0.00	1.00	2.03	
Analysis of Gait & Posture in three subsequent visits	First visit	0.25	3.00	4.00	1.47	Chi-Square=31.586 Df=2 P=0.000
	Second Visit	3.00	4.00	4.00	2.16	
	Third visit	3.25	4.00	5.00	2.38	
Analysis of language and vision in three subsequent visits	First visit	6.00	6.00	7.00	1.78	Chi-Square=10.857 Df=2 P=0.004
	Second Visit	6.00	6.00	7.00	1.97	
	Third visit	6.00	7.00	7.00	2.25	

*Df=degree of freedom

Table 4: Descriptive summary of NIHSS* assessment for three follow up visits

Statistics	First Visit	Second Visit	Third Visit
Mean	11.56±0.890	8.00±0.616	7.03±0.549
95% Confidence Interval for Mean	(Lower bound) 9.75 (Upper bound) 13.38	(Lower bound) 6.74 (Upper bound) 9.26	(Lower bound) 5.91 (Upper bound) 8.15
Median	11.50	8.00	7.00
Variance	25.351	12.129	9.644
Standard Deviation	5.035	3.483	3.106
Minimum	3	3	3
Maximum	21	15	15
Range	18	12	12

*NIHSS=National Institute of Health Stroke Scale

Table 5: Descriptive statistics of MRS* scores achieved by the group in three follow up visits

Follow up	n	Percentiles		
		25 th	50 th (median)	75 th
MRS first visit	40	4.00	4.00	5.00
MRS second visit	40	4.00	4.00	4.00
MRS third visit	40	3.00	4.00	4.00

*MRS scores=Modified Rankin Scale scores

centre in northwest India, in which the mean age of the patients was 58 ± 13 years.^[3]

In the current study, 70% of the total cases having a stroke episode were male. Similar observations were seen in a study conducted by Pandian *et al.* (2013) in a tertiary care center in northwest India where 67.7% stroke patients were male.^[3]

In the present study, most of the patients were illiterate; housewives contributed the major part. Most of the patients had distorted knowledge about stroke that mislead about prognosis and perceived slow and obscured progress of the disease. Knowledge of stroke is quite poor among people living in the developing world.^[16] In a study conducted in Northwest India,

neither the patient with stroke nor their relatives realized that the symptoms were because of stroke in the majority of cases, and only one third of the study cohort correctly identified the brain as the organ affected by stroke.^[17]

The current study showed that there was a gradual increase in muscle strength of upper limb and lower limb, when assessed in the course of time through follow up visits ($P = 0.000$). Up to second visit, a steady gain in power was noticed but after that, a plateau stage was noticed, as there could be the influence of age; severity of stroke and non-adherence to treatment on recovery. There was a significant improvement ($P = 0.000$) in sensation of upper and lower limb of the group but the stroke survivors still had a problem in performing fine motor skills as results were not the same for fine movements of hand ($P = 0.368$). In gait and posture of participants a gradual improvement ($P = 0.000$) was noticed during course of study. The incomprehensibility of the participants improved in time ($P = 0.004$) and those who were unable to express and communicate later showed signs of progress.

Assessment with MRS showed that although between 1st and 2nd follow-up disability status showed no significant difference ($P = 0.637$), there was a significant improvement in

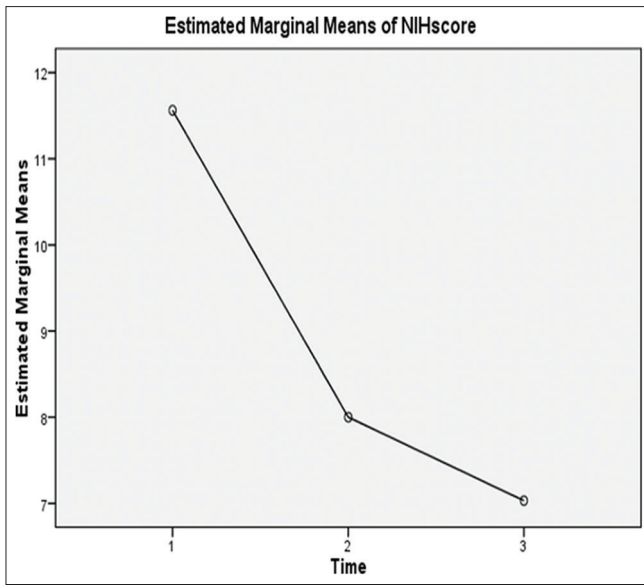


Figure 1: Profile Plot

Table 6: Friedman Test as non-parametric test detecting difference among groups

Follow up visits	Mean Rank	Statistic	Value
MRSf (first visit)	2.15	Chi-Square	7.600
MRSs (second visit)	2.10	Df*	2
MRSst (third visit)	1.75	P	0.022

*Df=degree of freedom

disability score from 2nd visit to 3rd visit ($P = 0.002$). It can be assessed from the current study that at home setting, 6 months post-stroke episode patients were still unable to carry out all previous activities, had difficulty in walking without assistance and require some help. Tomašević *et al.* 2015, in their prospective study, showed a statistically significant improvement ($P < 0.01$) in the average values of modified Rankin scale during the rehabilitation treatment of stroke patients.^[18]

To the best of our knowledge this study is one of the pioneer studies in India and possibly the first study in Central India which speaks about community-based follow-up of stroke survivors. The strength of this study lies in using more than one scale (NIHSS & MRS) to measure the effects of stroke in a community setting. This study bridges the gap between individual medicine and population medicine by showing the real time application of the principles of internal medicine in community setting. Stroke survivors are either missed or get unnoticed by our health system because our traditional model of healthcare does not have any provision for follow-up of these patients in the community. Post-stroke disability is a major cause of concern for the Stroke survivors. It is imperative and of utmost importance to follow Stroke survivors in the community to offer them efficient primary care services in order to provide proper rehabilitation. This is where the role of primary care physicians comes in, who are the first point of contact for these patients. Primary care physicians can not only look after follow-up of

such patients and their rehabilitation but also can play a vital role in the community by conducting information, education and communication (IEC) campaigns in the community and creating awareness in the community regarding Stroke and its risk factors.

Limitations

This study also has limitations as it does not claim any generalization of findings because of non-representative sample size. Also, MRS used in this study has a significant subjective element, so an over interpretation of the event may be a possibility. Subgroup analysis in certain cases is limited to 32 persons as 8 persons died during follow-up. This may significantly affect the directions of the result which was not addressed.

Conclusion

Quantitative scales largely showed on a primary basis that on the physical dimension of the disease the effects of stroke were affecting the functioning of the body at optimum capacity and harmony. There was an improvement in muscle power, sensation in the upper and lower limb, gait, and posture as well as language and vision in the patients in three subsequent visits. There was no significant difference in the fine movements of the patients. There was a gradual improvement in NIH score and there was a dominant presence of moderate-severe disability among the patients.

This study reveals that after the discharge from the healthcare institution, Stroke patients still suffer less than optimum health. Based on these evidences there must be a suitable optimum continuum of health and care services tailored to the need of patients because health is supposed to be a perfect condition in every dimension. Hence as a policy matter, intervention strategies should not be directed only up to hospital premises but their extension to the point of care is a must. This study provides an indirect need to strengthen primary healthcare and community-based care. Traditionally hospital-oriented medicine and community-oriented medicine are working in isolation and compartmentalization, but they should operate in a complementary and supra synergistic manner. Only then a gamut of the preventive, curative and rehabilitative services can be rendered to the patients.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Key Messages

There must be a suitable optimum continuum of health and care services tailored to the need of patients because health is

supposed to be a perfect condition in every dimension. Hence as a policy matter, intervention strategies should not be directed only up to hospital premises but their extension to the point of care is a must. This study provides an indirect need to strengthen primary healthcare and community-based care.

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Conflicts of interest

There are no conflicts of interest.

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