Original Research Article

Assessment of quality of life among stroke survivors: a longitudinal study

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ABSTRACT

Background: Quality of life (QoL) among stroke survivors is a concern which has not received sufficient attention in India. The objective of the study was to assess the quality of life of stroke survivors in rural population of Chikkaballapur district, Karnataka.
Methods: A community based longitudinal study was done amongst the 150 incident stroke cases registered during the period from March 2013 to November 2014 and who survived beyond 28 days. The cases were enrolled and interviewed using a semi-structured questionnaire and were followed up for 6th month period. QoL was assessed at baseline (at 28 days), at 3rd month and 6th Month using Stroke Specific QoL scale (SSQoL) and Barthel index (BI).
Results: The mean age of the persons with stroke was 61.3±15 years with a majority being males (69.3%). Baseline median score (IQR) of SSQoL at 28th day was poor i.e. 131 (77-183). Among the 150 cases, 136 (91%) survived until the end of 6th month. The overall QOL gradually improved to 182 (133-213) and 185 (147-213) at 3rd and 6th month respectively and similar improvement was seen individually in physical, psychological and social domains as well and on multivariate logistic regression age <60 years and few disturbed consciousness among the stroke survivors during the 6th month follow up were found to be predictors for improved quality of life.
Conclusions: QoL showed significant improvements in all physical, psychological and social domains by the end of the 6th month of follow up.

Keywords: Stroke survivors, Longitudinal study, Rural area, Quality of life, Stroke specific quality of life scale, Risk factors, Physical domain, Psychological domain, Social domain, Population based stroke registry, Non communicable disease. Barthel index

INTRODUCTION

Stroke is often a catastrophic event affecting all aspects of an individual's life. Currently, stroke outcome assessments are often limited to the resulting neurological impairment and functional disability. It is also important to evaluate the total influence of the event on a patient's well-being. According to the World Health Organization (WHO) stroke is defined as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin.[1] Annually, 15 million people worldwide suffer from stroke. Of these, 5 million die and another 5 million are left permanently disabled, placing a burden on family and community. Stroke burden is projected to rise from

around 38 million disability adjusted life years (DALYs) globally in 1990 to 61 million DALYs in 2020.[2] According to the India stroke factsheet updated in 2012, the estimated age-adjusted prevalence rate for stroke ranges between 84- 262/100,000 in rural and between 334- 424/100,000 in urban areas.[3]

Stroke has multitude of negative consequences on an individual's life ranging from institutionalization, and loss of independence to cognitive and communication difficulties. This requires a major adjustment in the social function and psychology of stroke survivors. It has a detrimental effect, both on short term and/or long term QoL.[4-8]

According to WHO, Quality of life is defined as "Individuals' perception of their life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.[9]

Many stroke survivors experience feelings of hopelessness, helplessness, anxiety, and dehumanization.[10-15] After an episode of stroke, QoL is reported to have decreased by more than 40% compared with pre-stroke QoL.[16] This reduction is pronounced, even when no or minimal physical impairment is present. Despite the high prevalence of stroke survivors, the impact on quality of life has not been estimated. Therefore, in this study, we intended to assess the QoL among stroke survivors, which can be helpful in developing more comprehensive and targeted interventions designed to maximise their recovery and improvement in health related quality of life.[7]

METHODS

Study design and setting

A community based longitudinal study was done wherein, all incident cases of stroke registered in the population based stroke registry formed the subject materials for this study in Chintamani town of Chikkaballapur district Taluk (Karnataka, India).

Source of data

This population based rural stroke registry established in rural area during the period March 2012 to December 2014 was supported by ICMR, which captured incident cases of stroke among 400 villages Chintamani town of Chikkaballapur district Taluk (Karnataka, India) covering a population of 1,91,122 (Census 2011).

### Study duration

March 2013-December 2014.

Ethical approval

The ethical approval was obtained from the Institutional Review Board (IRB) of M.S. Ramaiah Medical College, Bangalore before the commencement of the study.

Selection criteria

Initially 236 cases were identified as probable stroke cases by the Medico social workers which was later validated by the trained medical officer. Based on clinical examination and/ or radiological imaging evidence, 212 cases were confirmed as stroke cases and the rest as non-stroke cases which included Transient Ischemic Attack (TIA- focal neurological symptoms but lasting less than 24 hours), subdural and epidural haemorrhage, stroke mimics such as bell's palsy, etc.

Of the 212 cases, 179 were first ever stroke cases and 33 were recurrent stroke cases (Figure 1).
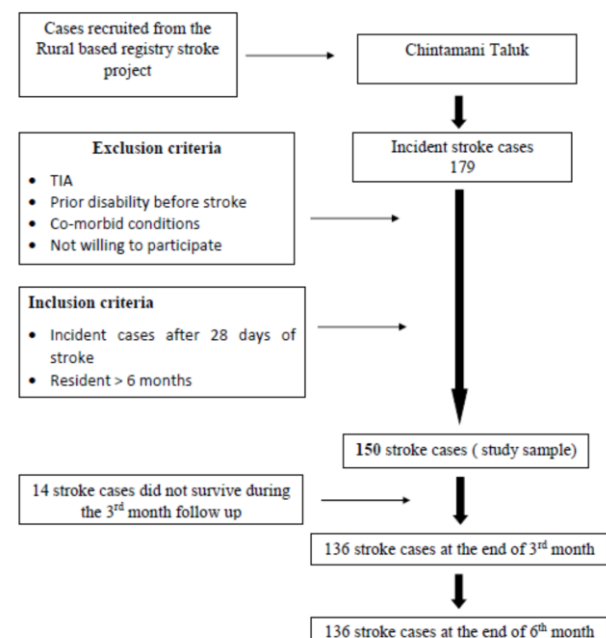
Figure 1: Flow chart on recruitment of the study participants.

Inclusion criteria

First ever stroke cases who survived beyond 28 days of stroke occurrence and those who have been a residing for more than six months in the study area were included.

Exclusion criteria

Those who had co-morbid conditions such as known end stage renal diseases and cancer and those who had disability prior to occurrence of stroke due to other causes were excluded from the study.

Sample size

The sample size for the present study was estimated based on a study carried out on quality of life among stroke survivors conducted by Artal et al.[17] Based on the findings of the above study, it was estimated to include 150 stroke survivors for the present study with a relative precision of 8% on quality of life and a desired confidence level of 95%.[17]

Among the 179 first ever stroke cases, consecutive cases registered in the registry were included till the required sample size of 150 was achieved.

The first author, conducted the study, after obtaining ethical clearance by the institutional ethical committee. The subjects enrolled were traced back to their residence and thorough rapport was established with the family members. The purpose of the study was explained and informed consent was obtained from the cases and care givers as appropriate. Baseline data on socio – demographic profile such as age, literacy status, marital status, occupation and monthly income based on updated B.G. Prasad classification (2015) was collected in a pretested semi structured questionnaire using interview technique at 28th day.[18] QoL was assessed employing a validated questionnaire of SSQoL and Barthel's index (BI) after 28 days of stroke and the same was assessed during the follow up period at 3rd and 6th month.[19,20]

Tool employed

The questionnaire consisted of 2 parts

Part A consisted of basic socio-demographic details (age, gender, marital status, educational qualifications, and occupation of the stroke survivors), co-morbidities, type of stroke, clinical features, history of transient ischemic attack.

Part B consisted of assessment of Qol using Stroke Specific Quality of life (SSQoL)[19] and Activities of daily living using Barthel's Index(BI) also to assess the level of dependency which also have a bearing on the quality of life of the stroke survivors.

A) The SSQoL tool on validation showed a good internal consistency and reliability (Cronbachs alpha ≥0.70).[19] SSQoL has a set of 49 items and 12 domain questionnaire which measure the strain related to provision of care. It's a three response sets on a 5-point Likert scale: namely

- Amount of help required to do specific tasks, ranging from No help…. Total help,
- Amount of trouble experienced when attempting tasks, ranging from Unable to do it to….No trouble at all, and
- Degree of agreement with statements regarding their functioning, ranging from Strongly agree to Strongly disagree.

The point of reference for all items was the past one week. All items were scored from 1 to 5, with higher scores representing more normal function.

(Scoring: each item was scored with the following key- Total help - Couldn't do it at all - strongly agree 1 A lot of help - a lot of trouble - moderately agree 2, some help - Some trouble - neither agree nor disagree 3, a little help - a little trouble - moderately disagree 4, no help needed - no trouble at all - strongly disagree 5)

B) Barthel index (BI) was used to assess the activities of daily living among the stroke survivors. This tool showed good internal consistency and reliability (Cronbachs alpha –0.87-0.92).[20] Barthel scale is an ordinal scale used to measure performance in activities of daily living (ADL). Each performance item was rated on this scale with a given number of points assigned to each level or ranking. It used ten variables describing ADL and mobility. A higher number was associated with a greater likelihood of being able to live at home with a degree of independence following discharge from hospital.[20]

The operational definition for the study adopted was based on the operational definition as defined by WHO.[1]

Those cases presented with symptoms of unilateral or bilateral weakness of the limbs which was sudden in onset lasting for more than 24 hrs, with/without slurred speech, facial palsy, hemiplegic gait and based on the history. These cases were clinically confirmed by the neurologist.

Follow up assessment

Survivors were contacted at third and at sixth month after the onset of stroke i.e. after the first visit, and a face to face interview was conducted after obtaining prior permission. Those survivors who presented with severe cognitive impairment or dysphasia, proxy respondent were used as a reliable source of information. QoL was assessed employing SSQoL instrument along with BI.

Statistical analysis

Total score for all the domains for each of the case as well as all cases were computed. The quantitative values such as age, quality of life score were expressed as mean (standard deviation) and median (Inter quartile range). Categorical variables like socio-demographic profile were expressed with frequency and percentages and 95% confidence interval. Associations of various factors with quality of life were assessed by employing Fischer's exact test. The median score for quality of life at different points of follow up was tested for statistical significance by employing Friedman test.

The total score of each individual was dichotomised based on the median SSQoL score noted at the 6th month. The scores were categorised into 2 groups based on the

Likert scale grading of the SSQoL. Patients who scored 5, which represented 'no help by the patient required' for each of the 49 items were categorised into one category as 'improved'. The rest were into the other category which represented 'little help required by the patient'. Association of the various factors such as demographic was evaluated between the above categories. Univariate analysis was undertaken to determine the association of various factors with quality of life. Odd's ratios along with 95% CI were estimated. Further to evaluate the independent predictors for quality of life, in addition to those factors which revealed statistical significance p≤0.05, some of the other factors which had p=0.025 were also included for multiple logistic regression analysis.

The data was analysed using SPSS version IBM SPS 18.0. Statistical significance was considered p<0.05.

RESULTS

Baseline results

In the present study, 150 stroke survivors were interviewed, among them 104 (69%) were males and 46 (31%) were females. The mean (SD) age of the persons with stroke was 61.33 (15) years. In the age group of 65–74 years, males and females accounted for 32% and 28% respectively. The difference in the distribution of stroke cases between different age groups was not found to be statistically significant (p=0.455) among males and females (Figure 2). The percentage of stroke cases among the young i.e. <40 years contributed for 11.7% only.
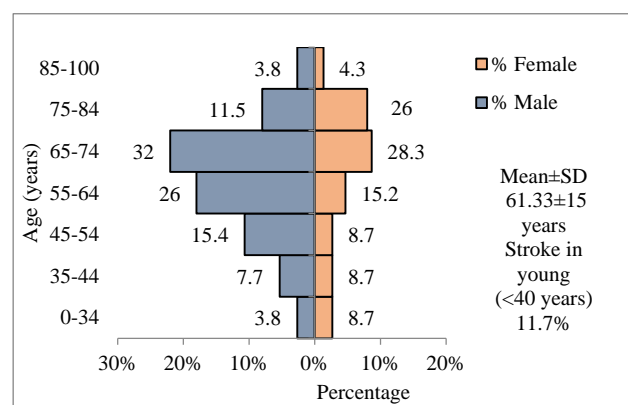
**Figure 2: Age and sex wise distribution of the stroke cases (n=150).**

Most of the stroke survivors were not literate (55.3%) and the difference in educational status among males and females was found to be statistically significant (p<0.04). Majority of the stroke survivors belonged to Hindu religion (85%) and 75.3% were married. It was found that 66% of the stroke survivors belonged to poor socioeconomic status and majority of the stroke survivors were agriculturist by occupation. Majority of them belonged to professional and semi-professional

occupational group 50 (33%). The difference in occupational status among males and females was found to be statistically significant (p<0.001).

Table 1: Baseline characteristics of the stroke survivors.

Variables	Levels	N (%)
Sex	Male	104 (69.3)
	Female	46 (30.7)
Age (years)	≤34	8 (5.3)
	35-44	12 (8)
	45-54	20 (13.3)
	55-64	34 (22.7)
	65-74	46 (30.7)
	75-84	24 (16)
	≥85	6 (4)
Marital status	Married	113 (75.3)
	Unmarried	1 (0.7)
	Divorced/separated	3 (2)
	Widow/widower	33 (22)
Religion	Hindu	127 (85)
	Muslim	22 (15)
	Christian	1 (1)
Socio-economic class (According to B.G. Prasad classification)	High	2 (1)
	Upper middle	10 (7)
	Lower middle	39 (26)
	Poor	99 (66)
No. of family members	1-4	50 (33)
	5-9	90 (60)
	≥10	10 (7)
Subtype of stroke	Ischemic stroke	52 (35)
	Intracerebral hemorrhage	5 (3)
	Unspecified type	93 (62)
Total		150

In this study, 50 (33%) persons with stroke belonged to families having family size of 1-4. The mean (SD) family size population was found to be 5.53 (2.41) (Table 1).
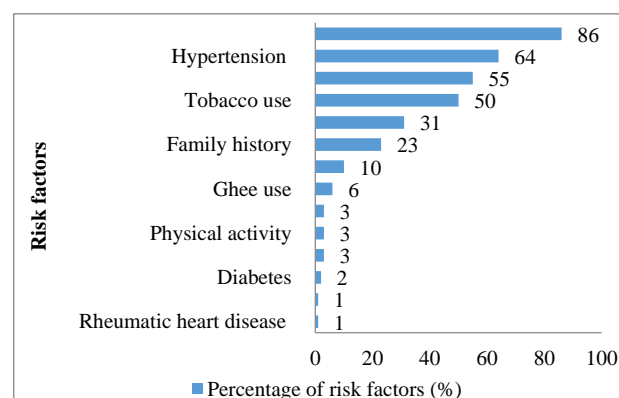
Figure 3: Distribution of risk factors among stroke survivors.

In this study, 35% had documented ischemic stroke while majority were unspecified type (Table 1). As regards to the treatment received by the patients, traditional treatment was sought by 36 (24%), allopathy 36 (24%), ayurvedic treatment 19 (13%) and multiple treatment 59 (40%) on first occasion. The multiple treatments consisted of various combinations of the above type of treatments. Out of 150 persons with stroke, 96 (64%) had history of hypertension. TIA as being well known risk factor as well being early warnings which helps in predicting stroke in future was seen in 10% of cases in our study (Figure 3).

As regards to symptoms, 56% of the persons with stroke had right sided weakness, 39% had left sided weakness and 5% on the both sides. Almost all the patients (98%) had limb weakness followed by the speech disturbances. The other symptoms such as disturbed consciousness, blurred/double vision, and impaired memory were present in almost similar proportions (Table 2).

Table 2: Distribution of presenting symptoms among the persons with stroke.

Symptoms	No. (%)
Disturbed consciousness	78 (52)
Speech disturbances	107 (71)
Limb weakness	147 (98)
Double vision/blurred vision	68 (45)
Impaired memory	68 (45)

Status and quality of life during follow up period

Of the 150 stroke cases followed up 136 cases survived at 3rd and 6th month of follow up. The stroke patients who died was due to different reasons not only due to stroke but other reasons such accidents, suicide etc. The quality of life assessment was done by employing SSQoL was carried out at 28 days, 3rd and 6th month. The median quality of life score according to various domains have been presented in Table 3.

Table 3: Distribution of domain wise stroke specific quality of life scores among the persons with stroke.

Median (IQR)*				
SSQOL components	After 28 days	3rd month	6th month	P value*
Physical component	58 (20-82)	80 (60-100)	82 (65-100)	<0.0001
Psychological component	63 (41-75)	75 (56-80)	75 (64-80)	<0.0001
Social relationship component	19 (7-29)	27 (18-35)	28 (18-35)	<0.0001

*Friedman test.

Table 4: Activities of daily living assessed using Barthel index among persons with stroke.

Grades of dependency	After 28 days of stroke N (%)	At 3rd month N (%)	At 6th month N (%)
Total dependent (0-20)	33 (22)	4 (2.7)	2 (1.3)
Severely dependent (25-55)	55 (36.7)	24 (16)	10 (6.7)
Moderately dependent (60-90)	62 (41.3)	108 (72)	124 (82.7)
Independent (95-100)	0	1 (0.7)	1 (0.7)

Distribution of SSQoL scores during the follow up period

It was found that the there was an improvement in the quality of life according to SSQOL, i.e. after 28 days of stroke, immaterial of the domains, the median score (Inter quartile range) was 131 (78-183), at 3rd month it was 182 (133-213) and at 6th month it was 185 (147-213). The differences in the median score of quality of life was found to be statistically significant over the time period.

The post hoc analysis revealed statistical significance between 28 days and 3 months (p<0.001). However, there was not much change in the median score between the 3rd and 6th month of follow up which indicated that there was no decline in the quality of life of the survivors.

Similar quality of life improvement was noted in all the domains of quality of life viz. physical, psychological and social component (Table 3).

Amongst the stroke survivors, at the end of 6th month, 45.5% of stroke survivors were found to be ≥185 score, according to the SSQoL, while 65.8% of patients had score of ≤185 score in the age group ≥61 years. Mean score for the age groups of ≤60 years and ≥61 years was 189.04 and 147.57 respectively and was found to be statistically significant with p<0.001. Negative correlation was found between actual score and the age (-0.204) and was found to be statistically significant.

It was also observed that the survivors have gradually shifted from being a totally as well as severely dependent survivors to moderately dependent Barthel index scale which conveys the dependency level of the stroke survivors by assessing the their activities of daily living at 28 days of stroke, 3rd and 6th month's i.e. over a period of time, out of 150 stroke survivors there was reduction in total dependency of persons with stroke after 28th day of stroke from 33 (22%) to 2 (1.3%) at 6th month of follow up (among 136 stroke survivors), 55 (36.7%) of

severely dependent stroke survivors at 28 day of stroke has reduced to 10 (6.7%) at 6th month (Table 4).

In this study we also observed that the quality of life of the stroke survivors improved by the end of 6th month as the dependency grades improved i.e. only 17% of stroke survivors are dependent to perform their daily activities of life.

Similarly, 61.6% of stroke survivors who had a score ≥185 score were either found to be moderately dependent or completely independent, according to Barthel index, while 16.7% of stroke survivors, who had a score of ≤184, were either totally or severely dependent. Correlation between the actual score of QoL and the BI was found to be negatively correlated i.e. –0.459 and was found to be statistically significant.

Table 5: Univariate analysis of stroke specific quality of life at 6th month.

Variables	Satisfied QoL (≥185)	QoL (≤184)	P value	Univariate OR (CI 95%)	Multivariate OR (CI 95%)
Age (years)					
≥61	35 (45.5)	48 (5.8)	0.012	0.434 (0.224-0.839)	0.438 (0.224-0.856)
<60	42 (54.5)	25 (34.2)			
Education					
Low (1-3)	4 (5.2)	4 (5.5)	0.938	0.945 (0.227-3.928)	NS
High (4-6)	73 (94.8)	69 (94.5)			
Occupation					
Non skilled (5-9)	30 (39)	34 (46.6)	0.346	0.732 (0.383-1.401)	NS
Skilled (1-4)	47 (61)	39 (53.4)			
Speech disturbances					
Yes	49 (63.6)	58 (79.5)	0.032	0.453 (0.217-0.942)	NS
No	28 (36.4)	15 (20.5)			
Disturbed consciousness					
Yes	33 (42.9)	45 (61.6)	0.021	0.467 (0.243-0.897)	0.471(0.242-0.917)
No	44 (61.1)	28 (38.4)			
Weakness					
Yes	74 (96.1)	73 (100)	0.088	1.986 (1.692-2.332)	NS
No	3 (3.9)	0			
No. of family members					
1-4	29 (37.7)	21 (28.8)	0.248	1.496 (0.754-2.968)	NS
5-15	48 (62.3)	52 (71.2)			
Gender					
Male	51 (66.2)	53 (72.6)	0.398	1.351 (0.672-2.716)	NS
Female	26 (33.8)	20 (27.4)			

The calculation of univariate odds ratio with various predictors revealed statistical significance with age, altered consciousness, activities of living as the significant predictor for an improved quality of life (OR 95% CI). The other predictors such as educational level, occupational level, symptoms of the patient and the number of family members did not reveal the statistical significance (Table 5). Further multivariate logistic regression analysis also revealed only the above two factors as the predictors i.e. age p<0.015 and disturbed consciousness p<0.026 for better quality of life among the stroke survivors.

DISCUSSION

Assessment of quality of life using SSQoL among stroke survivors and the effect of the type of stroke and type of therapy is the first step, to predict the kind of care needed by these patients and their families. Many studies have shown an increased prevalence of stroke in the young (<40 years) in India, ranging from 19% to 32% of all stroke cases.[21] Though there has been an increased prevalence of stroke in the young, many studies compared the age - specific incidence between India and other countries found that young adults in India are not more susceptible than their counterparts in the west.[22] In our present study it was observed that the demographic profile of our survivors was male preponderance and the proportion of persons with stroke among <40 years was found to be 11.7%.

In Indian culture, the joint family system ensures that every member of the family helps in care giving - spouse, in laws helps in physical management, men in organizing medicines and finances; and children in improving the quality of life of the persons with stroke. In a study done on caregiver stress in stroke survivor in a tertiary hospital in Pakistan found that stroke creates a situation where the

whole family gets involved. This is due to joint family system in Pakistan, where parents, spouse and children and other in laws live together under one roof where the responsibilities are shared.[23] In our study it was observed that those stroke survivors who had more number of family members, showed good quality of life among the stroke survivors at the 6th month (Table 5), even though it didn't show any significant difference during analysis.

There are hardly any comprehensive data in India about the implication of socioeconomic factors on stroke. Population-based surveys from South India conducted concurrently in rural and urban populations showed a higher prevalence of stroke in rural area. There is no published data on the prevalence of vascular risk factors separately among those below poverty line (mean annual income, less than US$ 1 per day).[24]

In a study done by Das et al found that lack of awareness of potential treatment availability was an important factor for the lack of motivation to obtain treatment.[24] In the present study, 66% stroke survivors belonged to poor socio-economic class according to updated B.G. Prasad classification.

In our study, we found that the quality of life of stroke survivors had improved after the first visit i.e. at third month of follow up, where the median score was 182 when compared to 131 which was seen after 28 days of stroke. There was also domain wise improvement at the third month of follow up. Also we found that as the BI score improved by the end of the 6th month of follow up i.e. the ability of the stroke survivors to perform their daily activities and the QoL also improved.

In a study done by Chandran et al on assessment of QoL of stroke survivors in a rural area of North Kerala, it was found that out of the 40 patients, only 2(5%) were fully independent, while majority needed assistance in varying degrees and few were totally bed ridden. This finding was one of the major determinants of QoL, which was found to be poor.[25]

In a study done by Jonsson found that the patients' most important determinants of QOL after 16 months were functional status, age and gender.[8]

The strength of our study is the low dropout rate in the form of loss to follow up. Of the 150 cases, 136 cases survived beyond 3 months who were completely followed up till the end of sixth month and no mortality was observed beyond three months.

The limitation of our study despite improvement in the quality of life of the stroke survivors it was not possible to assess what lead to improvement – whether environmental, medical influence or the natural disease process though the predictors have been identified.

CONCLUSION

In this present study we had witnessed that the quality of life has improved drastically after the initial visit of stroke. It also revealed a pressing need to educate the community on causes and prevention of risk factors of stroke, and need to refer and ensure transportation to tertiary care facilities within 4 hours of onset. It is important to strengthen primary health care services by focusing on risk factor intervention and targeting behaviour modification such as reduced smoking, alcohol & salt consumption pattern and increased physical activity and adopting healthy diet and also emphasis on the availability of the treatment and its accessibility rather than inculcating in the habit of multiple treatment options without giving enough time to react for the respective medications.

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