Assessment of quality of life of stroke survivors in a rural area of North Kerala, India

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ABSTRACT

Background: With increase in prevalence of stroke and life expectancy the quality of life of stroke survivors assumes importance. Despite advances in diagnosis and treatment of cerebrovascular accidents the survivors continue to experience low Quality of life (QoL) especially in developing countries. The objective of this study was to assess the quality of life among stroke survivors and the prevalence of depression among them.

Methods: Cross-sectional population based study was conducted in a rural area of North Kerala. Stroke survivors were interviewed at home to assess the quality of life and depression status. QOL was assessed using the Medical Outcomes 36-Item Short-Form Health Survey (SF-36), functional status using the modified Barthel index (MBI), and mood using the Beck’s Depression Inventory (BDI).

Results: A total of 40 patients (65.5% men, mean age 70.58±10.7 years) were interviewed. The mean MBI was 55.25±2.79, and the prevalence of unrecognized depression was 90%. 95 percent of patients needed varying degrees of care for their activities of daily living. The SF-36 scores of the patients were considerably lower than that of the general population especially in the areas of role limitation and physical functioning. Depression was more among older subjects and Depressed patients had lower MBI scores.

Conclusions: A significant proportion of stroke survivors continue to face limitations in their physical activities. In addition, majority have unrecognized depression that affects their QOL adversely.

Keywords: Stroke, Cerebrovascular accident, Depression, Quality of life

INTRODUCTION

Like all developing countries, stroke is emerging as a major public health problem in India. It is one of the leading causes of morbidity, mortality and disability in the developed as well as the developing countries. According to the WHO Collaborative Study in twelve countries, the stroke incidence rates were between 0.2-2.5/1000 population per year.¹ Initial community-based studies conducted in Vellore and Rohtak in India reported a very low prevalence of stroke but subsequent studies over the years have estimated the prevalence of stroke ranging from 127 – 220 per 100,000 population. The increase in prevalence has been attributed to an increase in life expectancy and the estimated Disability Adjusted Life Years (DALY’S) lost is as high as 597.6 per one hundred thousand.¹

Despite the increasing prevalence of stroke in the population, the quality of life (QOL) after stroke and the psychological impact it has on the person and his family is one of the least recognised aspects of the disease.
Stroke patients, in general have often been reported to have lower QOL which in turn is influenced by their functional status and depression post-stroke. The reported prevalence of post-stroke depression (PSD) varies from 20% to 65%. PSD is known to be related to dependence in activities of daily living (ADL) and to the severity of neurological deficits. However, even though prevalence studies on stroke have been conducted in India, studies related to QOL of stroke survivors and post-stroke depression are limited.

Cross-sectional field based studies carried out by personal interview method, in a home care setup, where the examiner can assess the patient’s mood, role limitations due to physical and emotional problems, general health, vitality, social functioning, by direct observation are ideal for assessing the QOL of stroke survivors. The present population-based study was carried out with the objective of assessing the quality of life of stroke survivors. Documentation of self-reported quality of life and its inclusion as an integral component of post-stroke assessment will help in planning interventions to improve the QOL of stroke survivors.

**Objectives**

The objectives of the present study were:

- To assess the quality of life among stroke survivors in a rural area of North Kerala.
- To find out the extent of disability among the stroke survivors.
- To assess the prevalence of post-stroke depression.

**METHODS**

**Study design**

A cross sectional study design was used.

**Study setting**

This field-based study was conducted in Mavoor Panchayath situated in Kozhikode district in Northern part of the state of Kerala, India. The total population of the Panchayath is around 29700. The primary health care facility in this area is the Community Health Centre (CHC), Cheroopa which is the rural practice area of Government Medical College Hospital, Kozhikode and is situated 14 km away from this institution. A list of all cases of both communicable and non-communicable diseases in the area is maintained by the health workers at the CHC. This list includes cases reporting to the CHC as well as data on diseases collected by the health workers from their respective field areas during house visits. The list of diseases is updated regularly.

**Study period**

The study was conducted during April-May, 2010.

**Case definition**

A confirmed case of Cerebrovascular Accident (stroke) diagnosed and treated from a tertiary health care facility and presently residing at home in Cheroopa panchayath.

**Exclusion criteria**

Patients with markedly decreased level of consciousness, those having previous psychiatric illnesses and those with significant cognitive and language impairments that prevented them from answering questions reliably were excluded from the study.

**Ethical considerations**

The study protocol was approved by the Institutional Research Committee and The Institutional Ethics Committee of Government Medical College Kozhikode. Care was taken to maintain the confidentiality of study participants.

**Methodology**

A list of all the patients diagnosed to have Cerebrovascular Accident (stroke) residing in the study area was obtained from CHC Cheroopa. Their addresses were obtained with the help of the female health workers. The stroke survivors were visited at their houses and the data from participants were obtained by semi-structured questionnaire by personally interviewing them after obtaining informed consent from the patients/caregivers. In case a participant could not be interviewed on the first visit two repeat home visits were made to ensure maximum participation. In addition to collecting socio-demographic details, the following assessments were also undertaken.

**Evaluation of quality of life**

The health-related quality of life of the participants were assessed using the Medical Outcomes 36-item Short Form Health Survey (SF-36). SF-36 is a multipurpose, short-form health survey with 36 questions which yields an 8 scale profile of the functional health and well-being scores as well as psychometrically based physical and mental health summary measures. Using SF-36, 8 health domains, namely: physical functioning, role limitations due to physical problems, emotional well-being, role limitations due to emotional problems, general health, vitality and social functioning was assessed. The SF-36 has been validated for use in the Indian population.

**Evaluation of functional status**

The functional status of stroke survivors was assessed using the Modified Barthel Index (MBI). MBI is a validated tool to screen for the assessment of self-care and mobility skills among stroke survivors. The categories assessed are feeding, dressing, personal
hygiene, bathing, toileting, bowel and bladder controls, ambulation, stair climbing. Each category of MBI is rated on a scale of one to five, with one indicating an inability to perform the task and five, full independence. Weighted scores would then help assess the functional status.

**Evaluation of depression**

In order to assess the patient’s mood, Beck’s Depression Inventory (BDI) was used. The 21 question BDI is a tool used to screen for depression. A subject getting a score of more than 10 is considered to be depressed.

The data was compiled using Microsoft Excel Spreadsheet and analysis was done using Statistical Package for Social Sciences (SPSS) statistical package version 17.

**RESULTS**

This field-based study included all patients with stroke in the study area, irrespective of severity and post-stroke duration. Total 47 patients with stroke were listed with help from the field health workers. Of these, 7 were excluded (4 deaths, 1 had psychiatric illness and 2 were not available during all the three visits). The remaining 40 patients formed the participants of the study. Prevalence of stroke was found to be 158.24/1,00,000 population.

**Profile of stroke cases**

The sociodemographic characteristics of the participants are given in Table 1. All of them were living with their families. Majority 27 (67.5%) were males. The mean age was 70.58 (±10.7years) (Range 40-94 years).

Based on the patient records, thrombosis was identified as the cause for the majority (92.5%) of CVA among the participants, with haemorrhage accounting for the rest. 15 patients (37.5%) had no addictions while 8(20%) had multiple addictions (viz smoking, alcohol, tobacco chewing).

All subjects had availed treatment during the acute phase of stroke from the nearest tertiary care centre - Government Medical College Kozhikode. In addition, 30(75%) had resorted to alternate systems of medicine (67.5% Ayurvedic 5%, Homoeopathic and 2.5% Naturopathy treatments) for long term stroke-related ailments.

Only 17 persons (42.5%) had undergone rehabilitation which included physiotherapy for 15 (88.23%) while 2 (11.77%) had received speech therapy also in addition to physiotherapy. Most of them had multiple co-morbid conditions which included Hypertension, Diabetes Mellitus, Hyperlipidemia and Coronary Heart disease (Table 2).

**Post-stroke quality of life**

The post stroke quality of life as measured by the SF 36 scores were low in all domains (Table 4). Scores of 100 in the domains of physical functioning, role limitations due to physical problems, bodily pain, social functioning and role limitations due to emotional problems, and scores of 50 in the three remaining domains of general health, vitality and mental health, indicate an absence of problems in these areas. The SF – 36 scores of our study population was compared with that of the scores for the general population in India and a study done in Singapore by Kong et al on stroke patients. The SF 36 scores of participants in the present study were considerably lower than the general population and also lower than that observed by Kong et al. The low scores in all domains indicate the low QOL experienced by the stroke survivors in our study. The lowest scores were observed in the domains of “role limitations due to physical problems and “physical function” Only 5 of the participants were still working post stroke with minor modifications in their work.

**Table 1: Clinical characteristics of stroke survivors.**

| Clinical parameter       | Percentage |
|--------------------------|------------|
| Age (in years)           |            |
| <50                      | 5          |
| 51-60                    | 10         |
| 61-70                    | 32.5       |
| 71-80                    | 35         |
| 81-90                    | 15         |
| >90                      | 2.5        |
| Duration post-stroke     |            |
| 1 year                   | 7.5        |
| >1 year                  | 92.5       |
| Sex                      |            |
| Male                     | 67.5       |
| Female                   | 32.5       |
| Marital status           |            |
| Single                   | 0          |
| Married                  | 42.5       |
| Widowed/Divorced         | 57.5       |
| Nature of stroke         |            |
| Infarct                  | 92.5       |
| Haemorrhage              | 7.5        |
| Mean MBI score           |            |
| 0 - 49 (severely dependent) | 30        |
| 50 - 74 (moderately dependent) | 40    |
| 75 - 90 (mildly dependent) | 22.5   |
| 91 - 99 (minimally dependent) | 2.5   |
| 100 (independent)        | 5          |
| Beck’s Depression Inventory |          |
| 10 or less (not depressed) | 10        |
| More than 10 (depressed) |            |
| - Mild mood disturbance  | 5          |
| - Borderline clinical depression | 15    |
| - Moderate depression    | 25         |
| - Severe depression      | 12.5       |
| - Extreme depression     | 32.5       |
**Functional status of stroke patients**

The functional status was assessed by Modified Barthel index (MBI) and the mean MBI score was 55.25±2.79 (maximum score which can be obtained is 100). On assessing the functional status of the patients for doing daily routine activities, out of the 40 patients, only 2(5%) were fully independent, while majority needed assistance in varying degrees and seven patients were totally bedridden (Table 1 and 3). All the subjects were being cared for by their relatives without employing formal or trained caregivers.

**Table 2: Risk factors and co-morbid conditions*.**

| Factor             | Percentage |
|--------------------|------------|
| Hypertension       | 83         |
| Diabetes mellitus  | 65         |
| Hyperlipidemia     | 30         |
| Coronary heart disease | 30    |
| Previous TIA       | Nil        |
| Smokers            | 38         |
| Tobacco chewing    | 20         |
| Alcoholics         | 30         |

*Multiple responses.

**Depression status**

Using the Beck’s depression Inventory 90% of the subjects were found to be suffering from varying degrees of depression and a sizeable proportion (32.5%) were having extreme depression. Of importance in this scenario is that none of the patients were diagnosed as having depression nor taking any medications for depression which brings to light the importance of unrecognised depression among stroke patients. In the present study, even though the number of males with depression (25) was more than the number of females (11) this was not statistically significant (chi square value =0.6, p = 0.43). The mean age of those with depression was found to be significantly higher (71.9 years) when compared to the mean age of those without depression (58.5) (p=0.03). Those with depression had a lower MBI score (51.94) when compared to those without depression (85) but this was not statistically significant (p=0.95).

**Table 3: Functional status of stroke survivors.**

| Function                     | Percentage |
|------------------------------|------------|
| Feeding                      |            |
| Unable                       | 15         |
| Needs help                   | 57.5       |
| Independent                  | 27.5       |
| Bathing                      |            |
| Dependent                    | 62.5       |
| Independent (or in shower)   | 37.5       |
| Grooming                     |            |
| Needs to help with personal care | 62.5   |
| Independent                  | 37.5       |
| Dressing                     |            |
| Dependent                    | 32.5       |
| Needs help, but can do half unaided | 37.5   |
| Independent (including buttons, zips) | 30      |
| Bowel                        |            |
| Incontinent                  | 12.5       |
| Occasional accident          | 22.5       |
| Continent                    | 65         |
| Bladder                      |            |
| Incontinent                  | 10         |
| Occasional accident          | 45         |
| Continent                    | 45         |
| Toilet use                   |            |
| Dependent                    | 17.5       |
| Needs some help              | 45         |
| Independent                  | 37.5       |
| Transfers                    |            |
| Unable                       | 12.5       |
| Major help                   | 17.5       |
| Minor help                   | 57.5       |
| Independent                  | 12.5       |
| Mobility                     |            |
| Immobile or<50 yards         | 17.5       |
| Wheel chair dependent        | 5          |
| Needs help of a person       | 40         |
| Independent (may use aids e.g. stick) | 37.5 |

**Table 4: SF-36 mean scores of stroke survivors.**

|                          | Present study | General population – India9 | Stroke survivors Singapore 12 |
|--------------------------|---------------|-----------------------------|-----------------------------|
| Physical functioning     | 21.00         | 93.59                       | 23.9                        |
| Role limitations due to physical problems | 1.87         | 78.53                       | 78.7                        |
| Bodily pain              | 71.18         | 83.80                       | 83.2                        |
| General Health           | 21.37         | 79.41                       | 70.1                        |
| Social functioning       | 30.31         | 80.82                       | 85.9                        |
| Vitality                 | 35.00         | 90.42                       | 64.9                        |
| Role limitations due to emotional problems | 23.33       | 79.89                       | 80.1                        |
| Emotional well being     | 50.20         | 86.16                       | 74.9                        |
DISCUSSION

Though several population-based surveys on stroke were conducted from different parts of India, these were primarily determined the prevalence of stroke and very few studies sought information about post-stroke depression and the post-stroke quality of life. According to the Asian Acute Stroke Advisory Panel, India is still ranked among the countries where the information on stroke is minimal.

Interestingly, a marked difference in the reported prevalence rates of stroke has been noted between various countries and even across communities within the same nation. The prevalence of stroke in this study population (158.24/100,000 population) was comparatively on the lower side. Analysis of community surveys from different regions of India shows a crude stroke prevalence rate of about 203 per 100,000 population above 20 years of age. A community-based survey in Kolkata revealed a stroke prevalence rate of 545 per 100,000 population, which is equal to or higher than that reported from developed countries. With an increase in life expectancy resulting in an increase in the size of the population at risk an increase in the prevalence of stroke is expected in India.

More than 90% of the stroke was due to infarction in the present study which is similar to studies conducted elsewhere which show that 70-80% of cases stroke is caused by brain infarctions, 9-15% by intracerebral hemorrhages and in about 10% by subarachnoid hemorrhages. An increase in the cases of stroke was observed with increasing age in our study but after 80 yrs the prevalence decreased probably due to a lesser number of at-risk population after 80 years or due to mortality. This increase with advancing age has been observed in many studies. Our study also showed a male preponderance among stroke patients. Other studies have demonstrated the increase is generally greater in males below 65 years of age than females in the same age group, but equalises with increasing age.

The quality of life is defined as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns”. The post-stroke quality of life as measured by the SF 36 scores were low in all domains when compared with normal Indian population. The lowest score being in the domain of “Role limitation” and “physical domain”. This finding suggests that many of these patients still encountered limitations or difficulties with their physical activities. This finding is corroborated by the relatively low mean MBI score of 55.25 which indicates that these patients were dependent even for activities of daily living ranging from feeding, dressing, grooming to walking.

The QOL of stroke survivors in our study is also considerably less when compared to study done by Kong et al in Singapore among stroke survivors. These results indicate that even though the prevalence of stroke may be low in our population the quality of life of stroke survivors is very low. Role limitations both due to physical and emotional problems contributed greatly to a low QOL, in addition, to decrease in health and vitality.

The majority of the subjects either were unable or needed help to perform their day to day activities like eating, dressing, bathing etc. Poor outcome in functional recovery and lowered quality of life is likely due to lack of rehabilitation and related treatment facilities as evidenced in our study - only a small percentage of the subjects were undergoing rehabilitation.

Post-stroke depression (PSD) is considered as the most frequent and important neuropsychiatric consequence of stroke since approximately one-third of stroke survivors experience major depression. The reported prevalence of PSD varies from 20% to 65% depending on the selection of patients, diagnostic criteria and the time elapsed after stroke.

The prevalence of PSD in our population was much higher (90%) than these figures with a significant proportion (32.5%) suffering from extreme depression. PSD is related to the severity of neurological deficits and to dependence in Activities of daily living (ADL). Also, communicative disorders such as aphasia and cognitive impairment may markedly contribute to the severity and persistence of depression. The present study population having a low quality of life and a high level of dependency might have contributed to the high prevalence of depression in the population. Older patients and males were found to be more depressed in our study contrary to epidemiologic data from around the world which demonstrate that PSD is more common in women than in men. A hospital based study at NIMHANS Bangalore showed a prevalence the prevalence of depression to be 80% among patients undergoing neurological rehabilitation. An association between depression and impaired social functioning has also been reported in several studies. The reduced social contacts of depressed stroke patients may be a cause as well as a result of depression. Though effective and safe drugs are available for treatment little effort is being done for detection and treatment of PSD as evidenced by the fact that all the cases of PSD in our study were unrecongnised.

Limitations

Even though the study was conducted in 2010 the results of the study are relevant even now considering the fact that not many population-based studies have been done to assess the QoL among stroke survivors in India.
CONCLUSION

Patients with stroke have impaired QoL. Role limitations and physical disability influence adversely the quality of life as do other domains. There is a high prevalence of unrecongnised depression among stroke survivors. The results of the study emphasise the importance of the multidimensional evaluations of the quality of life of post-stroke patients. Periodic screening of chronic cases for depression is recommended in view of the high prevalence of depression among stroke survivors. The study also calls for community-based rehabilitative approaches including continuous and coordinated counselling and support at the primary care level to improve the quality of life and assist the patients towards achieving independence in activities of daily living and return to some form of gainful employment.

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REFERENCES

1. Park K. Epidemiology of chronic non-communicable diseases and conditions. In: Park’s textbook of preventive and social medicine. 20th ed. Jabalpur: Banarsidas Bhanot. 2009:327-328.
2. Das SK, Banerjee TK. Stroke Indian Scenario. Circulation. AHA Journals org. 2008.
3. Wyller TB, Holmen J, Laake P, Laake K. Correlates of subjective well-being in stroke patients. Stroke. 1998;29:363-7.
4. Primeau F. Post-stroke depression: a critical review of the literature. Can J Psychiatry. 1988;33: 757-65.
5. Robinson RG. Neuropsychiatric consequences of stroke. Annu Rev Med. 1997;48:217-29.
6. Kotila M, Numminen H, Waltimo O, Kaste M. Depression after stroke. Results of the Finnstroke study. Stroke. 1998;29:368-72.
7. Determinants of Caregiving Burden and Quality of Life in Caregivers of Stroke Patients, Emily McCullagh, MRCP; Gavin Brigstocke, MBBS; Nora Donaldson, PhD Lalit Kalra, PhD, FRCP, Department of Stroke Medicine (E.M., G.B., L.K.), Guy’s, King’s, and St Thomas’s School of Medicine, King’s College, London, UK;
8. Jenkinson C, Coulter A, Wright L. Short form (SF-36) health survey questionnaire: normative data for adults of working age. Br Med J. 1993;306:1437-44.
9. Sinha R, Wim JA van den Heuvel, Arokiasamy P. Validity and reliability of MOS short form health survey (SF-36) for use in India. Indian J Community Medicine. 2013;38(1):22-6.
10. Shah A, Vanclay F, Cooper B. Improving the sensitivity of the Barthels index for stroke rehabilitation. J Clin Epidemiol. 1989;42:703-9.
11. Beck AT, Ward CH, Mendelsohn M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry. 1961;4:561-71.
12. Kong KH, Yang SY. Health-related quality of life among chronic stroke survivors attending a rehabilitation clinic. Singapore Med J. 2006;47(3): 213-8.
13. Asian Acute Stroke Advisory Panel. Stroke epidemiological data of nine Asian countries. J Med Assoc Thai. 2000;83:1-7.
14. Das SK, Banerjee TK, Biswas A, Roy T, Raut DK, Mukherjee CS, et al. A prospective community based study of stroke in Kolkata, India. Stroke. 2007;38:906-10.
15. Bonita R, Beaglehole R. The enigma of the decline in stroke deaths in the United States-the search for an explanation. Stroke. 1996;27:370-2.
16. Numminen H, Kotila M, Waltimo O, Aho K, Kaste M. (1996) Declining incidence and mortality rates of stroke in Finland from 1972 to1991. Results of three population-based stroke registers. Stroke. 1996;27:1487-91.
17. Kaste M, Fogelholm R, Rissanen A. Economic burden of stroke and the evaluation of new therapies. Public Health. 1998;112:103-12.
18. Rissanen A. Cerebrovascular disease in the Jyväskylä region, Central Finland. University of Kuopio, Kuopio. 1992.
19. WHOQOL group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychol Med. 1998;28:551-8.
20. Anderson CS, Linto J, Steward-Wynne EG. A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. Stroke. 1995;26:843-9.
21. Robinson RG, Bolla-Wilson K, Kaplan E, Lipsey JR, Price TR. Depression influences intellectual impairment in stroke patients. Br J Psychiatry. 1986;148:541-7.
22. Kurtzke JF. Epidemiology of cerebrovascular disease. In: McDowell FH, Caplan LR eds. Cerebrovascular survey report. Bethesda: NINDS, 1985:1-33.
23. Gupta A, Deepika S, Taly AB, Srivastava A, Surender V, et al. Quality of life and psychological problems in patients undergoing neurological rehabilitation. Annals Indian academy of Neurology. 2008;11(4):225-30.

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