Original Research Article

Functional Independence, Quality of Life and Participation of Stroke Survivors in the Rural Community- A Cross-Sectional Survey

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ABSTRACT

Background: In low- and middle-income countries (LMICs) like India, most stroke survivors reside in rural communities deprived of comprehensive rehabilitation, often resulting in long-term disabilities. The objective of our study was to identify the level of functional independence, quality of life and community integration of stroke survivors and to find the burden and quality of life of their primary caregivers.

Study design: A cross-sectional survey was conducted.

Study setting: The study was conducted in a rural community setting served by a tertiary care hospital in South India.

Method: A total of 30 stroke survivors and their primary caregivers were included. Demographic and stroke-related information was gathered from our database, and clinical characteristics were obtained using self-designed data form. Modified Barthel Index (MBI), Fugl-Meyer Assessment of Upper Extremity (FMA-UE), World Health Organization Quality of Life-BREF (WHOQOL-BREF), National Institute of Health Stroke Scale (NIHSS), Community Integration Questionnaire (CIQ) and Caregiver Burden Scale (CBS) were used as outcome measures.

Results: Participants showed a moderate level of impairment (mean ± SD 34±24) and independence (mean ± SD 67±28), with a low level of community reintegration (mean ± SD 4±6) and quality of life. Caregivers of stroke survivors showed a moderate to severe burden (41±19). The quality of life of caregivers was better than the quality of life of stroke survivors in all the Quality-of-Life domains ($p<0.01$). The caregiver burden moderately correlates with all their Quality-of-Life domains: psychological domain ($r = -0.507$; $p=0.004$), social relationship domain ($r = -0.506$; $p=0.004$), and environment domain ($r = -0.663$; $p<0.01$), but not in the physical health domain ($r = -0.218$; $p=0.247$).

Conclusion: Stroke survivors in rural South India showed moderate functional independence, while caregivers faced moderate to severe burden. The study highlights the need for accessible, community-based rehabilitation and support systems to improve the quality of life for both groups.

Keywords: functional independence; participation; quality of life; rehabilitation; stroke.

INTRODUCTION

Stroke is the second leading cause of death and third leading cause of death and disability in the world (Feigin et al., 2022). Stroke results in impairment in physical, psychological and social functions, leading to dependence in Activities of Daily Living (ADL) and reduced social participation, which in turn influences the Quality of Life (QoL) of stroke survivors (Kim et al., 2014). The treatment of these deficits is mainly focused on the acute and sub-acute phases as most of the recovery occurs in the first few months after the stroke. However, the majority of the stroke survivors are still left with long-term disability, including physical limitations, psychosocial and cognitive problems, even after undergoing rehabilitation (Lincoln et al., 2000; Patel et al., 2006; Wade et al., 1992). Literature also stated that 50% of the stroke survivors went back to the community with impairments, requiring assistance from caregivers along with continuous community support in order to promote community reintegration (Chau et al., 2009; Mayo et al., 2000).

Many studies have been conducted to explore the level of participation and QoL of stroke survivors in the community. A study conducted among 6-months post stroke survivors in the community found that 33% of the participants showed reduced participation in Basic Activities of Daily Living (BADL), 51% in household tasks, 50% in travel, and 53% in meaningful activities, which led to social isolation and reduced activity levels (Mayo et al., 2002). It was found in a survey that 60% of the stroke survivors were dependent in their BADL, and their QoL was significantly lower (Hackett et al., 2000). Another study also found that stroke survivors had lower QoL and were functionally dependent in their ADL (Parikh et al., 2018). A study conducted among Swedish population also found that stroke survivors, two years post-onset, have declined in their independence level after discharge, and they were more dependent in BADL and Instrumental Activities of Daily Living (IADL) (Grimby et al., 1998). These studies revealed that many stroke survivors are left with disability without continuous support from the community, which reduces their participation and QoL.

Caregivers play an important role in the care and recovery of stroke survivors (Chaiyawat & Kulkantrakorn, 2012; Good et al., 2011), yet they are also impacted by the disabilities resulting from the stroke (Ganjiwale et al., 2016). Caregivers may experience a burden that leads to the deterioration of their health and QoL. The burden increases with the duration of caregiving (Gbiri et al., 2015). Caregivers undergo problems such as loss of independence, fatigue, inadequate time for self-care, and managing physical symptoms (Grant et al., 2004). Studies showed that the burden was more on female caregivers and on caregivers of severe stroke survivors (Menon et al., 2017). Therefore, the objective of our study was to identify the level of functional independence, QoL, and community participation among stroke survivors residing in rural South Indian community and to find the burden and QoL of primary caregivers of stroke survivors.

STUDY OBJECTIVES:

1. To identify the functional independence, QoL, and community participation of stroke survivors living in the rural South Indian community.
2. To compare the QoL of stroke survivors and their primary caregivers living in the rural South Indian community.
3. To correlate the burden and QoL of primary caregivers of stroke survivors living in the rural South Indian community.

METHODS

PARTICIPANTS:

The study included 30 stroke survivors and their primary caregivers living in a rural South Indian community. The details of stroke survivors were identified from the database of the department of Community Health of a tertiary care hospital. The inclusion criteria for participants were persons with a diagnosis of first-ever ischemic or haemorrhagic stroke within 2 years from the date of onset, those who were able to communicate verbally or non-verbally, and who were willing to participate in the study. Persons who had difficulty in comprehending and responding to the questionnaires were excluded from the study. The criteria for caregivers were caregivers who are significant family members and provided support with the basic needs of stroke survivors and were willing to give informed consent to participate in the study.

STUDY SETTING:

The study was conducted in a rural community block of a tertiary care hospital in South India. The block consists of 88 villages with a total population of approximately one lakh twenty thousand people.

STUDY DESIGN:

A cross-sectional survey was done to obtain the data from the participants. The data collection was done for 4 months, from December 2017 to March 2018. The outcome measures were administered by trained occupational therapists, and the approximate duration taken to administer the measures was 45 minutes.

OUTCOME MEASURES:

Demographic and stroke-related information was gathered from the database and from the stroke survivors and their caregivers using a self-designed data form. The functional independence was assessed using the Modified Barthel Index (MBI). The MBI is a measure of activities of daily living, which shows the degree of independence of a person from any assistance. It covers 10 domains of functioning: bowel control, bladder control, as well as help with grooming, toilet use, feeding, transfers, walking, dressing, climbing stairs, and bathing. It is a 10-item scale where each activity is given one of the five levels of dependency ranging from 0 (unable to perform task) to a maximum of 5, 10, or 15 (fully independent). Each activity is given a score ranging from 0 (unable to perform task) to a maximum of 5, 10, or 15 (fully independent- exact score depends on the activity being evaluated). A total score is obtained by summing points for each of the items. Total scores may range from 0 to 100, with higher scores indicating greater independence. This scale was found to have good internal consistency, the Cronbach's alpha = 0.89, and good concurrent validity (Hsueh et al., 2001; Ohura et al., 2011).

The motor assessment was done using the Fugl-Meyer assessment of Upper Extremity (FMA-UE). The FMA-UE is a stroke-specific, performance-based impairment index. It is designed to assess motor functioning, balance, sensation, and joint functioning in patients with post-stroke hemiplegia. The interrater reliability of the scale is found to be 0.97, and the construct validity of the tool was found to be r=0.86-0.89 (Sanford et al., 1993).

QoL of stroke survivors and caregivers was assessed using the World Health Organization Quality of Life- BREF (WHOQOL-BREF). The WHOQOL-BREF contains a total of 26 questions. To provide a broad assessment, one item from each of the 24 facets contained in the WHOQOL-100 has been included. In addition, two items from the overall quality of life and general health facet have been included. Overall, it consists of four domains, including physical domain, psychological domain, social domain, and environmental domain. The WHOQOL-BREF presented good reliability (Cronbach's alpha 0.9207), converging validity (0.382 < r < 0.753; p < 0.001), discriminant validity, and criterion validity (0.554 < r < 0.778; p < 0.001) (Ohaeri & Awadalla, 2009).

Community reintegration was assessed using the Community Integration Questionnaire (CIQ). The CIQ consists of a total of 15 questions. The overall score, which represents a summation of the scores from individual questions, can range from 0 to 29. A higher score indicates greater integration, and a lower score reflects less integration. The scale also had excellent test-retest reliability (ICC= 0.9970) (Singh & Sharma, 2015).

The caregivers' burden was assessed using the Caregiver Burden Scale (CBS). CBS consists of a total of 21 questions. It is used to assess perceived burden among people caring for others with disabilities. For each item, caregivers indicate how often they felt that way, and responses are rated from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, and 4 = nearly always). The internal consistency of the CBS was high (Cronbach's α 0.875). The item total correlations ranged from 0.138 to 0.708 and were all statistically significant (P < 0.01) (Lu et al., 2009).

Stroke severity was assessed by using the National Institute of Health Stroke Scale (NIHSS). NIHSS is a tool used to quantify the impairment caused by a stroke. The NIHSS is composed of 11 items, each of which scores a specific ability between 0 and 4. For each item, a score of 0 typically indicates normal function in that specific ability, while a higher score is indicative of some level of impairment. The individual scores from each item are summed to calculate a patient's total NIHSS score. The maximum possible score is 42, with the minimum score being 0. The NIHSS has moderate-to-high reliability (intra-rater =0.66 to 0.77; inter-rater= 0.69) and moderate concurrent validity (r = 0.61 and 0.68) (Kasner et al., 1999).

SAMPLE SIZE:

The sample size was calculated based on mean ± SD of NIHSS score reported (Raju et al., 2010) as 2.1 ±2.1. Assuming a 25% shift on both sides, a precision of 0.525 was considered. So, to detect a mean level of 2.1 with a precision of 0.525 and SD of 2.1, with 95 % CI, a sample size of 64 was estimated.

DATA ANALYSIS:

The data was summarized as frequency and percentage for categorical variables such as age, gender, duration of stroke, and stroke severity. For continuous variables such as FMA-UE, MBI, and QoL, mean ± SD was used. The comparison of demographic variables with functional outcomes was done using the Wilcoxon rank sum test (Mann-Whitney test). The association of caregiver burden with QoL was done using Pearson Chi-square correlation. The comparison between QoL of stroke survivors and their caregivers was done using independent t-tests. A p-value of 0.05 was considered statistically significant.

STATEMENT OF ETHICS:

Ethical approval for the study was obtained from the Institutional Research and Ethics Committee (IRB min No. 10962 dated 07.11.2017) before the commencement of the study.

RESULTS

The study included 30 stroke survivors and their caregivers living in the community. Initially, 38 potential stroke survivors were identified from the database. Among those, 2 persons could not be located, and 6 persons had deceased (16%), resulting in a final sample of 30 participants. The demographic and clinical characteristics of stroke survivors are shown in Table **1**. The demographic characteristics of caregivers are shown in Table 2.

Table 1: Demographic and clinical characteristics of stroke survivors

VARIABLES		n (%)
Age	<=60	14 (47)
	>60	16 (53)
Gender	Male	12 (40)
	Female	18 (60)
Duration of stroke	<1 year	20 (67)
	>1 year	10 (33)
NIHSS	1-mild	12 (40)
	2-moderate	16 (53)
	3-severe	2 (7)

Table 2: Demographic characteristics of caregivers

VARIABLES		n (%)
Age	<=60	26 (87)
	>60	4 (13)
Gender	Male	7 (23)
	Female	23 (77)
Hours of assistance	<3 hrs.	8 (27)
	3-6 hrs.	4 (13)
	>6 hrs.	18 (60)
Relation	Spouse	13 (43)
	Son/daughter	10 (33)
	Relative	7 (23)

Table **3** shows the level of impairment, functional independence, and community integration of stroke survivors living in the community.

The mean FMA, MBI & CIQ scores were 34±24; 67±28; 4±6, respectively. According to FMA and MBI, higher score indicates less impairment and better functional status respectively. The results indicated that the participants showed moderate levels of impairment and functional status. Out of 30 participants, the majority (87%) were not reintegrated into the community and have scored 0 (n=13) and less than 10 (n=13) in the CIQ. The mean duration of post stroke was 8 ± 6 months.

Table 3: Level of impairment status, functional independence, and community integration of stroke survivors

VARIABLES	Mean (SD)
FMA-UE	34 ± 24

Modified Barthel Index	67 ± 28
Community Integration Questionnaire	4 ± 6

Table **4** shows the comparison of QoL of stroke survivors and their caregivers.

There is a significant difference found in all four domains of WHOQOL-BREF between stroke survivors and their caregivers- Psychological domain (p<0.01), physical health domain (p<0.01), social relationship domain (p<0.01), and environment domain (p= 0.003).

Table 4: Comparison of Quality of Life of stroke survivors and their caregivers

VARIABLE	Stroke survivors n = 30	Caregivers n = 30	p-value
	Mean (SD)	Mean (SD)	
WHOQOL-BREF			
Physical domain	43 ±11	56 ±10	<0.01
Psychological domain	36 ±12	57 ±10	<0.01
Social domain	42 ±14	55 ±14	<0.01
Environmental domain	45 ±15	56 ±13	0.003

*p value was set at 0.05

Table **5** shows the correlation between caregivers' QoL and their burden.

A significant negative correlation was found between caregiver burden and psychological (r = -0. 507; p=0.004), social relationship (r = -0. 506; p=0.004), and environment domains (r = -0. 663; p<0.01) of WHOQOL-BREF. There was no significant relationship found between physical health (r = -0. 218; p=0.247) and burden of the caregivers.

Table 5: Correlation between caregivers' Quality of Life and burden

VARIABLE	N	CBS	
		r	p-value
Physical health	30	-0.218	0.247
Psychological		-0.507	0.004*
Social relations		-0.506	0.004*
Environment		-0.663	<0.01*

*p value was set at 0.05

DISCUSSION

Stroke survivors residing in rural communities are deprived of comprehensive rehabilitation due to inaccessibility, lack of awareness, and financial resources. This may lead to increased physical and psychological impairments, reduced activity and participation levels, and reduced QoL and life satisfaction. In recent times, researchers and rehabilitation professionals have been focusing more on providing rehabilitation services in the community (Pitthayapong et al., 2017; Sureshkumar et al., 2015). However, rehabilitation strategies developed for one community may not be generalizable to other communities due to various factors such as education level, people's beliefs, government health policies, and lack of resources. Understanding the stroke survivors and their caregivers' needs and expectations, caregiver burden, stroke survivors' level of functioning, participation, and QoL will help in developing appropriate rehabilitation strategies for stroke survivors residing in our study setting.

On studying the level of impairment, functional independence and community reintegration, it was found that stroke survivors scored an average of 34 ± 24 on the FMA-UE, 67 ± 28 on the MBI and 4 ± 6 on the CIQ, which showed that they had moderate level of impairment, moderate independence in their ADL and a very low level of community reintegration (refer to Table 3). On comparing the severity of stroke of our study participants, our results showed a similar pattern with a study done in UK, which reported severity of their stroke participants as mild (33%), moderate (30%) and severe (19%) and death (18%) (Magalhães et al., 2014) at the end of 3 months post-stroke. Their participants were taken from both rural and urban areas, and they have used the Modified Rankin Scale to classify stroke survivors' severity. Our data suggested that the majority of our rural stroke survivors fall under the mild and moderate category, and the death rate was 15%. Though many of them had mild (40%) to moderate (53%) stroke based on NIHSS, they were found to have significant impairment, activity limitation, and participation at the end of 8 months post stroke. Stroke survivors who were more physically independent were able to reintegrate better into the community (Hamzat et al., 2014). One of the studies also reported low levels of community reintegration (11%) among stroke survivors in Hong Kong (Pang et al., 2007).

Many long-term studies on stroke survivors have shown an association between impairment, ADL, and participation. The ADL and participation in house chores and leisure activities have been found to improve stroke survivors' muscle strength and endurance (Mutai et al., 2016). Few prospective studies have examined changes in the ADL in home-dwelling stroke survivors and have reported only a slight increase in ADL scores over time (Hartman-Maeir et al., 2007; Kim et al., 1999; Whiting et al., 2011). All the studies mentioned above clearly demonstrated that community-dwelling stroke survivors have lesser engagement in their ADL and social participation, which in turn influence their impairment status. All the 30 stroke survivors who participated in our study did not undergo proper rehabilitation after the acute management from the base hospital and were discharged to the community very early after the onset of the stroke. Despite the absence of comprehensive rehabilitation, the majority of these stroke survivors were regularly followed up at their homes by our community healthcare team comprising doctors, nurses, occupational therapists, and community health aids, which likely contributed to their moderate level independence after stroke.

Stroke survivors in our study showed lower QoL scores in all four domains (physical 43 ± 11; psychological 36 ± 12; social 42 ± 14 and environmental 45 ± 15) (refer to Table 4) compared to previously published literature (physical 54 ± 15; psychological 58 ± 15; social 68 ± 20; environmental 68 ± 18) from an urban community in India (Raju et al., 2010). Poorer QoL was associated with greater levels of physical disability and reduced social interaction in a study done in Tanzania, which also reported that demographic variables appeared to be much less significant (Howitt et al., 2011). These findings are in concordance with our results.

On comparing the QoL of stroke survivors and their caregivers, the QoL of caregivers was found to be better in all four domains of WHOQOL-BREF (refer to Table 4). These findings were similar to previous studies where caregivers' QoL was better than the patients' QoL (Dayapoglu & Tan, 2010; Ganjiwale et al., 2016). The comparison between the QoL of stroke survivors and their caregivers provides important contextual insights into the distinct challenges faced by each group, which can inform targeted interventions. Stroke survivors often experience physical and functional limitations, such as reduced mobility, difficulty performing ADL, and dependency on caregivers. These factors directly impact their physical health domain of QoL and contribute to emotional distress due to loss of independence (Kim et al., 2014). Understanding stroke survivors' lower QoL highlights the need for accessible rehabilitation services that address functional independence and emotional well-being. Caregivers face a different set of challenges, primarily stemming from emotional and social burdens associated with caregiving responsibilities. While their physical health may not be as severely impacted as stroke survivors, caregivers often experience stress, fatigue, and social isolation, which affect their psychological and social domains of QoL (Gbiri et al., 2015; Grant et al., 2004). Comparing their QoL with stroke survivors helps contextualize how caregiving roles influence their overall well-being.

On studying the correlation between caregivers' burden with their QoL, a moderate correlation was found in all the domains except for the physical health domain (refer to Table 5). Most of the caregivers in our study were women (77%), who were spouses (43%), and who offered assistance for more than 6 hours a day (60%). Therefore, they would have experienced more burden due to the continuous care they had to give to the stroke survivors and due to their role shift, which would have caused additional responsibilities in the family. Our findings were similar to two studies conducted in India, which stated that women who were spouses and those who have provided longer hours of assistance had increased burden (Bhattacharjee et al., 2012; Menon et al., 2017).

CONCLUSIONS

Stroke survivors in rural South India demonstrated moderate levels of functional independence, highlighting the urgent need for accessible and effective rehabilitation services tailored to their unique challenges. The comparison between the QoL of stroke survivors and their caregivers provides important contextual insights into the distinct challenges faced by each group, which can inform targeted interventions. Caregivers, on the other hand, experienced moderate to severe burden, underscoring the necessity of implementing robust caregiver support systems. The observed correlations between caregiver burden and Quality-of-Life domains, except physical health, emphasize the multifaceted impact of caregiving on overall well-being. These findings call for decentralized, low-cost rehabilitation models and community-based interventions to improve the quality of life for both stroke survivors and their caregivers in resource-limited rural settings.

LIMITATIONS

One of the important limitations in our study was sample selection. We have restricted our inclusion criteria to stroke survivors within two years from the date of onset. Another limitation was that all the stroke survivors residing in the community were not included due to inaccessibility and time constraints. This survey could have extended to other stroke survivors in the entire community for the generalization of results.

Ethical approval: Ethical approval was sought and obtained before the commencement of this study. The participants gave their informed consent after the purpose and nature of the study were explained to them.

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Declaration of interest: The authors report no conflict of interest.

Data Availability Statement: The data that support the findings of this study are available from the corresponding author upon reasonable request.

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