

## ORIGINAL RESEARCH



# Stroke patients' outcomes and satisfaction with care at discharge from four referral hospitals in Malawi: A cross-sectional descriptive study in limited resource

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## Abstract

### Background

Stroke is the fourth leading cause of mortality and disability in Malawi. There is paucity of studies reporting on acute stroke functional outcomes, quality of life and satisfaction with care among patients with stroke. This study aimed to determine stroke outcomes and satisfaction with care in the country's central hospitals.

### Methods

A descriptive cross-sectional study, recruiting 114 adult patients with stroke and their caregivers, was done. FIM, EQ-5D-5L, SASC and C-SASC were used to collect data. Univariate associations were assessed using the Kruskal-Wallis Test for categorical variables and the Wilcoxon Rank Sum Test for continuous variables.

### Results

With 79% of the original study sample taking part, there was improvement in patients' functional status at discharge compared to on admission with notable improvement in self-care ( $p < 0.001$ ), sphincter control ( $p < 0.001$ ), locomotion ( $p < 0.001$ ), and social cognition ( $p < 0.001$ ), but no significant improvement in transfers ( $p = 1.000$ ), and communication ( $p = 0.865$ ). Satisfaction with care was high, with no significant differences between males and females ( $p = 0.415$ ), age in years ( $p = 0.397$ ), and distance to the clinic ( $p = 0.615$ ). Satisfaction ratings were also high from caregivers' responses and their scores were not associated with age ( $p = 0.663$ ) or distance to the hospital ( $p = 0.872$ ). Quality of life was poor, most patients were either unable or had severe limitation in functional dimensions of mobility (22(28%)), self-care (19(25%)) and performance of usual activities (25(33%)). Every additional year in age was associated with average of 0.36 decrease in quality of life score coefficient, -0.36 (95% CI: -0.63; -0.10);  $p = 0.008$ .

### Conclusion

Patients with stroke experience improvement in functional outcomes on discharge compared to on admission. Patients and caregivers were satisfied with care provision despite having poor quality of life post stroke treatment. There is need to focus proven interventions on areas of stroke care that can impact patients' quality of life in resource limited settings.

**Key words:** acute stroke, patients' outcomes, patients' satisfaction, rehabilitation, nursing, medical care, central hospitals, Malawi

## Background

Stroke outcomes are an indicator of quality of stroke services provided<sup>1</sup>. There is a dearth of literature reporting on stroke outcomes in most sub-Saharan African countries including Malawi. A prospective study that investigated stroke outcomes among patients with HIV one year after stroke found that 53.4% of patients had poor outcomes including severe disability and death<sup>2</sup>. This study showed that poor stroke outcomes were independent of HIV infection.

Quality of life (QoL) post stroke is an appraisal of general wellbeing of individuals affected by stroke. Acute stroke is known to lower the QoL for its survivors through the disability it brings and associated emotional distress that could lead to depression. For example, in a Tanzanian study, 68% of all-ages patients with stroke gave up their work permanently, and experienced marked disability through failure to walk independently, to perform self-care and usual activities and exhibition of psych-affective disorders such as depression, and anxiety<sup>3</sup>. In Malawi, an interview-based study by Heikinheimo and Chimbayo was conducted, where 81 patients with stroke, who were followed up six months after stroke, revealed that "good" functional outcomes

in the domains of activities of daily living (ADLs) and communication was positively associated with better QoL. Women scored worse in the fatigue and cognition domains<sup>4</sup>. Older age was also associated with lower QoL in the ADLs domain.

Besides functional health outcomes and QoL, patients' satisfaction is an important indicator of the quality of care in a given setting<sup>5</sup>. This may explain the degree to which patients comply with their treatment; whereby the high satisfaction ratings may attract high level of adherence to treatment. Factors related to satisfaction include patients' sociodemographic characteristics, physical and psychological state, attitudes, and expectations of health care, as well as structure, process, and outcome of care<sup>6</sup>.

In this study, we describe functional outcomes among patients with stroke, their satisfaction with care and QoL after completing treatment in four referral hospitals in Malawi.

## Methods

### Research setting

This study was conducted in eight medical wards across the

four central hospitals in Malawi, which admit and manage patients with stroke. The hospitals are Kamuzu Central Hospital (KCH [Central region, Lilongwe]) with 1000 beds, Queen Elizabeth Central Hospital (QECH [Southern region, Blantyre]) with 1400 beds, Mzuzu Central Hospital (MCH [Northern region, Mzuzu]) with 306 beds, and Zomba Central Hospital (ZCH [Eastern region, Zomba]) with 500 beds. In all these hospitals, patients with stroke come into first contact with the hospital at the casualty, or emergency department, or Accident and Trauma Centre, as it called in different settings. In Malawi, there is basic physiotherapy service, which is currently restricted to central hospitals. In practice, physiotherapists assess patients with stroke and their progress to identify physiotherapy goals. Technically, during the acute phase, besides counselling patients with stroke and their caregivers, physiotherapists work on prevention of early stroke complications such as aspiration pneumonia and the deep venous thrombosis (DVT). As part of acute care, physiotherapists encourage early mobilization and positioning to prevent pressure sores, and proper feeding positioning to encourage function and prevent aspiration pneumonia during admission<sup>7</sup>.

### **Research design**

A descriptive cross-sectional study design was used. Patients and guardians completed paper questionnaires, which were electronically processed using a Microsoft Excel database. In this paper, we report quantitative data.

### **Study population and sampling**

In this hospital-based study, the entire population of patients with stroke was included as this is an optimal situation in a cross-sectional study<sup>8</sup>. The study population included 114 patients with stroke and their informal caregivers, admitted at the hospitals in the research setting between 1 April 2016 and 31 May 2016, and their informal caregivers. Inclusive sampling was used to recruit the participants.

### **Inclusion and exclusion criteria**

Patients' inclusion criteria were: (1) clinically diagnosed stroke by a qualified physician through history and physical examination (both parameters have been used in community studies with 92% sensitivity for diagnosing stroke and transient ischemic attack), (2) 18 years of age or older, (3) cognitively sound, able to speak and be understood, and (4) admitted to one of the four central hospitals. Informal caregivers were those persons who provided direct support and other caregiving roles to the person with stroke without compensation. Patients who were hemiplegic due to head injury were excluded.

### **Sampling and recruitment**

Three intern physiotherapists and one rehabilitation technician assisted with data collection, after undergoing study protocol training for the study. Each research assistant abstracted data from patients' records on a weekly basis to identify potential study participants. The assistant also relied on the hospital referral system, where the rounding doctors referred admitted stroke patients to the Physiotherapy Department. The eligibility screen was then applied to all those who were eligible to participate in the study. Data were then collected from eligible and consented patients, first on admission using the Functional Independence Measure (FIM). On discharge, the FIM was re-administered and other data collection instruments were equally administered as per

study protocol.

### **Outcomes and measurement**

The researchers used pre-validated tools to assess study outcomes. Stroke patient outcomes were measured through items contained in the FIM, which is a valid and reliable tool for evaluating patients with stroke on admission and at discharge to determine their function status, their follow up and disease progress<sup>9</sup>. The FIM scale contains 18 items; 13 items in physical or motor domains and 5 items in the cognition domain. Motor items measure self-care, sphincter control, locomotion, and transfer abilities. Cognitive ones evaluate communication and social cognition skills. For levels of independence, as measured by the FIM, each item is scored from 1 to 7, where 1 indicates total dependence and 7 indicate total independence. Possible scores range from 18 to 126. The higher the score, the greater the degree of independence in ADLs. Quality of life and self-rated health were assessed using the EQ-5D-5L which has both a descriptive system and EQ Visual analogue scale. The descriptive system comprises of 5 dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the 5 dimensions. The EQ visual analogue scale records the respondent's self-rated health on a 20-cm vertical line. The scale has endpoints labelled 'the best health you can imagine' and 'the worst health you can imagine'. This information is used as a quantitative measure of health as judged by the individual respondents. The EQ-5D-5L is a well-established tool for measuring quality of life<sup>10</sup>. Additionally, the EQ-5D-5L descriptive system as a generic health outcome measure has been reported to be valid among patients with acute stroke, demonstrating some psychometric advantages in comparison with the earlier version, EQ-5D-3L<sup>11</sup>. Patients' and care-givers' satisfaction with stroke care were measured using the Patient Satisfaction-With-Stroke-Care (SASC) hospital scale and Care-Giver Satisfaction-With-Stroke-Care (C-SASC) Hospital Scale. All the instruments were translated into the local language (Chichewa) by qualified and independent translators at the University of Malawi and piloted for face validity at Queen Elizabeth Central Hospital with positive feedback from participants.

### **Ethical considerations**

Ethical approval was received from the University of the Western Cape (registration number 15/6/31) and the College of Medicine Research and Ethics Committee (COMREC), University of Malawi (approval number P.10/15/1819). All participants gave a written or thumb print witnessed informed consent before participating in the study. Heads of each central hospital gave permission for the study to recruit within their hospital. Access to the data collected was limited only to study the staff to uphold confidentiality and privacy of study participants through protection, known only to the investigator.

### **Data analysis and interpretation**

Stata v13.0 (Stata Corp, Texas, USA) was used for data management and statistical analysis. Summary statistics were computed as median (interquartile range), having confirmed graphically using histograms that continuous variables were not normally distributed. All normally distributed variables

were summarised using means with standard deviation (SD). Univariate associations were assessed using the Kruskal-Wallis Test for categorical variables and the Wilcoxon Rank Sum Test for continuous variables due to the small number of participants in the study (N = 90). The correlation between two continuous variables was assessed using the Pearson product moment correlation coefficient (r). Simple bar graphs, pie charts, and scatter plots visualise the distribution of appropriate variables. One-way tabulation was used to compute proportions for categorical variables. Simple linear regression was used to investigate associations between two continuous variables.

## Results

Out of 114-person study sample, 9 died before discharge, 11 were excluded due to speech problems, and 4 were lost to unexpected discharge. This study, therefore, had complete data from 90 participants, representing 79% of the initial study population. Overall mean age was 58.6 years (SD=16.3) and 48 (53%) were male. The majority of the patients were recruited from Queen Elizabeth Central Hospital (QECH) (28; 31%) and Kamuzu Central Hospital (KHC) (27; 30%), while 19 (21%) and 16 (17%) were from Mzuzu and Zomba central hospitals (MCH and ZCH), respectively (Table 1). Comparable age ( $p=0.109$ ) distribution across the four hospitals was observed but there were significantly more male patients at KCH (17 [63%]) and MCH (14 [73%]), while QECH had more female patients (18 [64%]);  $p=0.041$ . Patients in QECH and MCH spent a significantly longer time in the hospital with median (interquartile range [IQR]) length of hospital stay (LOS) of 10.5 days (IQR: 5-18) and 12 days (IQR: 7-14), respectively, per the patient's satisfaction with in-patients Stroke Care (SASC) scale. This was significantly different from the median LOS of 6.5 days (IQR: 5-7.5) and 5 days (IQR: 4-10) for KCH and Zomba Central Hospitals (ZCH) ( $p=0.008$ ), respectively.

and 2 (IQR: 2-6) to 10 (IQR: 5-14) and 6 (IQR: 2-11), respectively. However, there was no significant improvement in transfers and communication ( $p$ -values $\geq 0.865$ ), which was the same across the four sites.

### *Satisfaction with care: Patients' and caregivers' perspective*

Patients' satisfaction with care was high, with a median score of 19.5 out of a maximum score of 28 (IQR: 15-23) and there was no significant difference between male (20 [IQR: 14-25]) and female (19 [IQR: 15.5-22.5]) patients,  $p=0.415$ . Similarly, satisfaction scores did not differ by age (years), with a coefficient of -0.04 (95% CI: (-0.14; 0.06);  $p=0.397$ . Satisfaction ratings were also high from caregivers' responses, with a median score of 24 (IQR: 21-27). However, female caregivers (25 [IQR: 21-29]) rated stroke care marginally more than their male counterparts: 23 [IQR: 20.5-26]),  $p=0.058$ . Again, caregivers' satisfaction scores were not associated with age: 0.02 (95% CI: -0.07; 0.1),  $p=0.663$ . There was a positive linear relationship between patient and caregivers' satisfaction scores with Pearson correlation coefficient ( $r$ ) = 0.66 (Figure 1).

### *Quality of life (QoL)*

QoL of stroke patients in this study is generally poor as evidenced by higher level scores of the ED 5D functional dimensions of mobility, self-care and performance of usual activities in Table 3. On mobility, most patients were either unable to walk (22 [29%]) or had severe problems with walking (18 [24%]). The majority of patients (19 [25%]) had severe problems with self-care seconded by 10 (13%) who were unable to perform self-care activities. Most patients were also unable to do their "usual" activities and the second majority experienced severe problems (25 [33%]) in doing the same. Patients, however, did not show increased levels of psych-affective disorders, most of the participants scored

**Table 1: Demographic characteristics of patients (N = 90), Hospital of study recruitment**

Variable		QECH		Lilongwe		Mzuzu		Zomba		p-value*
Number recruited (n, %)		28	31	27	30	19	21	16	17	
Age (years) (median (IQR))		59	(41;72)	60	(53;68)	70	(58;77)	53	(35;66)	0.109**
Sex: male (n, %)		10	35	17	63	14	73	7	43	0.041
Female (n, %)		18	64	10	37	5	26	9	66	
Length of hospital stay (LOS)	Median (IQR)	10.5	(5; 18)	6.5	(5; 7)	12				0.008

IQR: interquartile range \* Fisher's Exact test unless described otherwise \*\* Kruskal-Wallis test

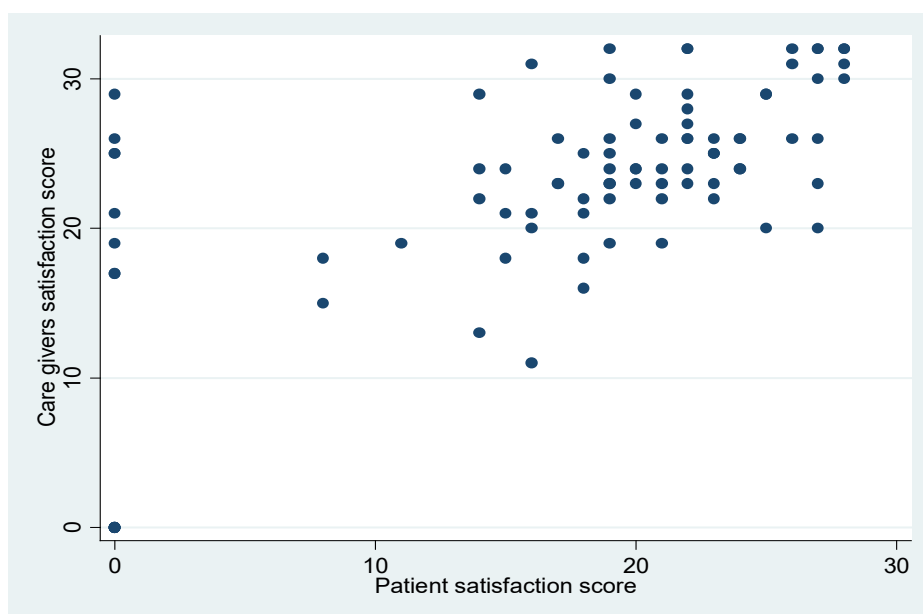
### *Functional Independence Measure (FIM)*

Overall, FIM-scores increased significantly between admission (median=51.5 IQR: 39-62) and discharge (median=70, IQR: 52-95) ( $p<0.001$ ). Significant improvements between admission and discharge existed in the following FIM components: self-care, sphincter control, locomotion and social cognition ( $p\leq 0.003$ ) (Table 2). Score for self-care increased from a median of 11 (IQR: 7-18) on admission to 20.5 (IQR: 12-31) on discharge. Similarly, sphincter control and locomotion improved from a median of 4 (IQR: 2-12)

low on pain or discomfort (19 [25%]), or moderate pain or discomfort (20 [27%]), and the majority did not feel anxious or depressed (19 [25%]), or were just moderately anxious or depressed (18 [24%]). On the Visual Analogue Scale (VAS), the participant's experience of "health today" was average, with a median VAS score of 50 out of 100 (IQR: 45-75). QoL was similar between male (median score 52.5 [IQR: 45-75]) and female patients (50 [IQR: 45-70]),  $p=0.307$ . Using a simple linear regression model, every additional year in age was associated with an average of 0.36 decrease in quality of

**Table 2: Functional Independence Measure (FIM) (N=90)**

	Admission		Discharge		p-value*
	Median	IQR	Median	IQR	
Selfcare	11	7; 18	20.5	12; 31	<0.001
A eating	3	2; 6	6	4; 7	<0.001
B grooming	1	1; 3	4	2; 6	<0.001
C bathing	1	1; 2	3	1; 5	<0.001
D dressing - upper body	1	1; 2	3	1; 5	<0.001
E dressing - lower body	1	1; 2	3	2; 6	<0.001
F toileting	1	1; 3	4	2; 6	<0.001
Sphincter control	4	2;12	10	5;14	<0.001
G Bladder management	2	1;6	6	3;7	<0.001
H Bowel management	2	1;6	6	3;7	<0.001
Transfers	3	3; 8	3	3; 8	1.000
I bed, chair, wheelchair	1	1; 3	1	1; 3	1.000
J toilet	1	1; 4	1	1; 4	1.000
K tub, shower	1	1; 3	1	1; 3	1.000
Locomotion	2	2; 6	6	2; 11	<0.001
L walk/wheelchair	1	1; 3.5	3	1; 6	<0.001
M stairs	1	1; 3	3	1; 5	<0.001
Communication	14	12; 14	14	13; 14	0.865
N comprehension	7	7; 7	7	7; 7	0.975
O expression	7	6; 7	7	7; 7	0.975
Social cognition	12	6; 14	14	10; 14	<0.001
P social interaction	6	3; 7	7	5; 7	<0.001
Q problem solving	5	3; 7	7	5; 7	<0.001
R memory	4	2; 6	6	3; 6	0.003



**Figure 1: Correlation between patients' and caregivers' satisfaction scores**  
 Correlation coefficient: 0.66

life score coefficient; -0.36 (95% CI: -0.63; -0.10); p=0.008.

**Discussion**

The main findings from this study were improved functional outcomes at discharge from four central hospitals among patients with stroke; high satisfaction ratings with stroke care by patients and care givers, although quality of life after the stroke episode was generally poor; and that patients with stroke spent relatively fewer days in the hospital compared patient length of hospital stay in some African countries. Stroke functional outcomes, perceived quality of life and satisfaction with care are used in rehabilitation to determine quality of stroke services<sup>1</sup>. Therefore, understanding these domains is a step towards identifying areas for improvement in stroke service provision. Despite resource constraints, patients with stroke had functional outcomes that significantly improved on discharge from the four central hospitals in Malawi. The improvement in patients’ functional status on discharge compared to on admission in most FIM components is both positive and interesting, given that Malawi is one the poorest countries with very limited health care resources

subtype or subgroup, all patients made clinically significant functional gains on completion of inpatient care<sup>13</sup>. We further note that despite notable improvement in self-care and locomotion FIM components, our patients still needed moderate assistance on discharge in those areas. Additionally, while there was significant progress in sphincter control from failure on admission to nearly full control at discharge, there was no significant improvement in all items related to transfers and communication. In transfers, stroke patients were still dependent at discharge. These findings imply that additional, well-focused care including effective inter-professional collaboration that ensure timely engagement of physiotherapy service may be needed to gain further improvement of patients with stroke<sup>13,14</sup>. Patients’ satisfaction with care is another critical indicator of the quality of care in a given setting<sup>5</sup>. In this study, patients and caregivers expressed high satisfaction with care with no differences among men and women, or by age. However, female care givers had significantly higher satisfaction ratings compared to male care givers. Care giving is generally performed by women in the Malawian culture, perhaps explaining the difference in care givers’ satisfaction ratings as female care givers tend to

**Table 3: Quality of life (QoL) items**

ED-5D Dimension & levels	Description of perceived problems	Number	Percentage
Mobility	Level 1 I have no problems in walking about	5	6.58
	Level 2 I have slight problems in walking about	19	25.00
	Level 3 I have moderate problems in walking about	12	15.79
	Level 4 I have severe problems in walking about	18	23.68
	Level 5 I am unable to walk about	22	28.95
Self-care	Level 1 I have no problems washing or dressing myself	2	2.63
	Level 2 I have slight problems washing or dressing myself	10	13.16
	Level 3 I have moderate problems washing or dressing myself	18	23.68
	Level 4 I have severe problems washing or dressing myself	19	25.00
	Level 5 I am unable to wash or dress myself	10	13.16
Usual activities	Level 1 I have no problems doing my usual activities	2	2.63
	Level 2 I have slight problems doing my usual activities	9	11.84
	Level 3 I have moderate problems doing my usual activities	8	10.53
	Level 4 I have severe problems doing my usual activities	25	32.89
	Level 5 I am unable to do my usual activities	32	42.11
Pain/discomfort	Level 1 I have no pain or discomfort	19	25.33
	Level 2 I have slight pain or discomfort	19	25.33
	Level 3 I have moderate pain or discomfort	20	26.67
	Level 4 I have severe pain or discomfort	12	16.00
	Level 5 I have extreme pain or discomfort	5	6.67
Anxiety/depression	Level 1 I am not anxious or depressed	19	25.33
	Level 2 I am slightly anxious or depressed	16	21.33
	Level 3 I am moderately anxious or depressed	18	24
	Level 4 I am severely anxious or depressed	7	9.33
	Level 5 I am extremely anxious or depressed	15	20.00

in general, and for managing stroke in particular<sup>12</sup>. In fact, there is no stroke unit and there are very limited qualified stroke specialists, with only one Medical Resonance Imaging (MRI) facility as a vital diagnostic equipment throughout the country. We believe that the general improvement in functional status of the patients is natural recovery, although the impact of therapy may not be completely ruled out. The positive findings in stroke functional outcomes based on FIM ratings in the current study are, however, comparable to findings in other similarly low-resource settings. For example, a study of hospitalised patients with stroke in a low resource setting in Singapore showed that regardless of the stroke

be more resilient in care giving roles based on observation. We also postulate the general increase in satisfaction ratings could be connected to lack of knowledge of “what is” and what “ought to be?”. Despite improvement in functional outcomes and high satisfaction scores, patients with stroke in this study had poor quality of life as measured by EQ-5D-5L and its associated Visual Analogue Scale (VAS)<sup>11</sup>. Most patients were either unable or had severe problems with walking, doing their self-care and usual activities. This is similar to a Tanzanian study, where 68% of patients with stroke of varying ages gave up their work permanently, and they also experienced marked disability, depression,

and anxiety<sup>5</sup>. Poor QoL in this study, is also similar to the findings of earlier studies<sup>14,15</sup>. We also found that as patients got older, they were more likely to have poorer QoL than younger patients. Similar observations were made by Dayapoglu et al<sup>16</sup> who found that patients aged 61 to 71 years had the lowest scores with regard to functional status, well-being and general health perception; and the lowest mean QoL score. Therefore, there is a need to focus on functional abilities when managing patients with stroke with the aim of improving their health-related quality of life. The current study also shows that stroke patients across the four central hospitals spent average of 8.5 days although those at Queen Elizabeth and Mzuzu Central Hospitals spent significantly longer in hospital when compared to LoS for stroke patients at Kamuzu and Zomba central hospitals, respectively. The average LoS is generally lower when compared to that reported by Heikinheimo et al<sup>2</sup>, who showed that the average hospital stay at Queen Elizabeth Central Hospital was 15.7 days, and that of a retrospective analysis of health records of stroke patients admitted into the medical wards of the University College Hospital, Ibadan, which found  $13.7 \pm 8.9$  as an average LoS<sup>17</sup>. However, a similar finding was recorded by Nakibuuka et al<sup>18</sup> in Uganda at Mulago national referral and teaching hospital where stroke patients had an average length of hospital stay of 8.9 days. Overall, reduction in hospital stay in the country's central hospitals could be a good development especially considering cost-related implications of acute stroke care. Saposnik et al<sup>19</sup> stated that length of stay is the major determinant of cost-determining factor during acute stroke hospitalization, an important consideration for limited resource areas such as Malawi.

Limitations of this study include the small sample size, and selection bias whereby only those who were able to understand and speak the spoken language were included. This left out some people with probably severe stroke disability in which case this study may underrepresented with this group. Other patients with mild stroke and not admitted to one of our sample hospitals are not represented in the current study. The quality of life findings may be spurious, as there were no comparison measurements. Finally, the comorbidities that potentially impact patient function and QOL have not been captured in the current study. Additionally, the current study was carried out at central hospitals, leaving out district hospitals that may be more active in managing and discharging stroke patients.

## Conclusion

The functional outcomes of patients with stroke in this cross-sectional study improved significantly on discharge compared to on admission status. Patients and caregivers showed that they were highly satisfied with the way care was provided despite having poor quality of life post-stroke treatment. There is a need to focus proven interventions on areas of stroke care that can impact the patients' quality of life in resource limited settings such as Malawi. Malawi could consider the introduction of specialized stroke care units which have been found to improve outcomes even in low to middle income countries<sup>20</sup>.

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