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Howitt SC, Jones MP, Jusabani A, Gray WK, Aris E, Mugusi F, Swai M, Walker RW. [A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania](#). *Journal of Neurology* 2011, 258(8), 1422-1430.

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<http://dx.doi.org/10.1007/s00415-011-5948-6>

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**Further information on publisher website:** <http://link.springer.com>

**Date deposited:** 6<sup>th</sup> November 2013

**Version of file:** Author final



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# A cross-sectional study of quality of life in incident stroke survivors in rural northern Tanzania

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**Word count:** Text 3646, Abstract 270, References 38, Tables 3.

**Key words:** Stroke, Tanzania, Quality of life, Community-dwelling

**EJN:** 4000 words, excluding tables and figures, but including all else. 6 tables or figures.

**Journal of Neurology:** 20 pages in total.

## ABSTRACT

**Background and purpose:** To evaluate changes to, and predictors of, quality of life (QOL) in a community-based cohort of stroke survivors from an earlier stroke incidence study in rural northern Tanzania.

**Methods** Patients were assessed 1-5 years after their incident stroke. The study cohort was compared to an age- and sex-matched control group from the same rural district within a cross-sectional design. Patients and controls were asked a series of questions relating to their QOL (WHOQOL-BREF), levels of anxiety and depression (HAD scale), cognitive function (CSI-D screening tool), socioeconomic status and demographic characteristics (e.g. age, sex, education, abode). Patients were further assessed for functional outcome and disability (Barthel index, modified Rankin scale), post-stroke care and psychosocial functioning.

**Results:** Patients (n = 58) were found to have significantly lower QOL than controls (n = 58) in all 6 domains of the WHOQOL-BREF. Gender, socioeconomic status, cognitive function and time elapsed since stroke were not associated with QOL. Older patients and those with more impaired motor function and disability (Barthel Index, modified Rankin score) had significantly poorer physical health related QOL. Greater anxiety and depression, reduced muscle power and less involvement in social events were significantly correlated with lower physical and psychological health related QOL.

**Conclusions:** To our knowledge this is the first long term study of quality of life in survivors of incident stroke in Sub-Saharan Africa (SSA). Poorer QOL was associated with greater levels of physical disability, anxiety and depression and reduced social interaction. Demographic factors appear to be much less significant. Modifying these QOL predictors could be important in planning effective post stroke care within a stretched healthcare system.

## Introduction

Stroke is the second leading cause of death worldwide according to the World Health Organisation (WHO) and many survivors are left with significant disability. The disease burden caused by stroke, as measured in disability adjusted life years (DALYs) is almost nine times higher in low and middle income countries, compared to high income nations [1,2]. The prevalence of morbidity related to stroke is set to escalate in the developing world as life expectancy increases and populations expand [3]. It is important that we establish the subjective impact of stroke on survivors in developing countries, and identify the factors predicting poor quality of life, so that we can strive to modify them. Quality of life data will highlight the pertinent need for allocation of health resources for the prevention and management of stroke at a community and a national level in low-income countries. Quality of life (QOL) is an important health outcome to measure following stroke, as it gives a holistic insight into the wide ranging effects that stroke can have on a person's physical, social and emotional health [4,5]. In a study analysing QOL in under 65 year old stroke survivors 4 years post stroke in Finland, results showed that despite the fact that 98% were living at home, 87% were independent in activities of daily living (ADLs) and 54% were gainfully employed, the QOL of most patients (83%) had not been restored to pre-stroke levels [6]. These findings are supported by a recent Canadian study [7]. The greatest perceived deterioration in QOL amongst stroke survivors was related to reduced participation in leisure activities and lack of employment. In contrast, an American study [8] found that QOL in stroke survivors at 1-3 years was relatively high compared to that of the background population. Other studies support this, indicating that 52-82% of long-term survivors were satisfied with their lives [9-11]. Although methodologically robust studies of post-stroke QOL in the developing world are few, a hospital-based Nigerian study revealed that stroke survivors reported lower levels of QOL than controls [12]. The controls used were relatives of the stroke patients. A psychological disorder or low education level were the best predictors of low QOL in the stroke group.

In recent years, there has been an increasing interest in the identification of stroke risk factors in the developing world [13-18]. However, rigorous research is lacking on the QOL and long-term outcomes of stroke survivors. Many previous studies of QOL in stroke survivors are limited by an absence of controls, a lack of standardisation of outcome scales and a selection bias due to patients only being recruited from hospitals [12,19,20]. Due to limited resources, high rates of early post-stroke mortality and individual health beliefs a large proportion of African stroke patients do not reach a hospital [21]. This means that those that attend hospital are often unrepresentative of the wider community of stroke cases, with only those who survive, or who have a more severe stroke, being seen. Therefore, community based research is vital to obtain representative data. In addition, some studies fail to specify the length of time since stroke and only follow-up patients in the short term [22]. One of the reasons for the lack of research in this area is that the practicalities of long term follow-up of stroke survivors are complex, especially in rural community settings where aids such as postal addresses and phone numbers are not normally available [23].

It is important that we establish the subjective impact of stroke on survivors in developing countries, and identify the factors predicting poor quality of life, so that we can strive to modify them [19]. A need for accurate and reliable research in this area has been highlighted by Fitzgerald *et al* and Akinpelu *et al* [20,24]. Such data will help to guide the allocation of health resources effectively for the prevention and management of stroke on a national level in poorer nations.

The aim of this study was to evaluate QOL in a cohort of stroke survivors from an incident population rural northern Tanzania [25]. Patients' QOL scores were compared to a group of age and sex matched controls from the same rural community. Associations between QOL scores and other variables (age, sex, anxiety, depression, dementia, socio-economic status etc.) were considered to try to establish which factors best predict QOL.

## **Patients and methods**

Patients were recruited from survivors of a previously published stroke incidence study in the rural Hai district of northern Tanzania from June 2003 to December 2007; only those who met the World Health Organisation criteria for stroke were included [25]. They were assessed as part of the current study between June and September 2008. This was 1-5 years post-stroke, depending on the date of their incident stroke. Controls were selected by convenience sampling of people from the same geographical area. Relatives and carers of stroke patients were excluded as potential controls. The control patients were selected by local healthcare workers from within the Hai district. In total 58 stroke patients and 58 controls consented to take part in the study. A favourable ethical opinion was obtained from the National Institute of Medical Research in Tanzania and from the Newcastle and North Tyneside joint Ethics Committee.

## **Measurement**

Assessment and examination of patients and carers was carried out by the physician study leads (SCH and MPJ), with local healthcare workers acting as translators and interpreters. Controls were assessed by either SCH, MPJ or one designated clinical assistant who had received training. Each patient and control was assessed using a series of well recognised scales and assessment tools during a 1-2 hour interview. Where the patient had a main carer they were also interviewed as part of the Community Screening Instrument for Dementia (CSI-D) protocol. Demographics (name, age, sex, abode, highest level of education) were obtained from patients, carers and controls. In cases where patients were unable to respond due to dysphasia or aphasia, demographic and other background information was sought from a relative or carer.

Patients and controls were assessed using:-

The WHOQOL-BREF [26]: This is a 26-item assessment of QOL which considers overall QOL and satisfaction with health, together with summary scores in domains of physical health (domain 1), psychological health (domain 2), social relationships (domain 3) and environment (domain 4). Raw scores are converted to a score from 0 to 100, with a higher score denoting higher QOL. In a case

where a value was missing the mean value for the other scores in that domain was substituted, in accordance with WHO guidelines for completing the WHOQOL-BREF.

Socioeconomic status was assessed using a 10-item questionnaire which covered areas including housing and land ownership. The Hospital Anxiety and Depression Scale (HAD) [27,28] and the CSI-D were also administered to patients and controls [29]. The CSI-D is a 34-item screening instrument for dementia in developing countries, consisting of two parts, one questionnaire directed at patients and the other at an informant or carer. Scores from patients and informants (carers) are weighted to give a global measure of dementia.

Patients, but not controls, were assessed using:-

The Barthel Index [30] and the Modified Rankin scale [31]: These are both measures of the functional independence of an individual with regard to carrying out activities of daily living (ADLs). Muscle power was measured using the Medical Research Council scale (0 - no movement, 1 – flicker, 2 - movement with gravity eliminated, 3 - movement against gravity, 4 – movement against gravity and some resistance by examiner, 5 – normal movement) [32]. Blood pressure was recorded whilst sitting using an A&D UA-767 bp monitor. Three measurements were taken one minute apart after five minutes resting quietly. An average of the last two readings was taken to try to ensure that a raised heart rate, and blood pressure, due to anxiety over medical procedures did not over estimate the prevalence of hypertension in our cohort. A reading of greater than 90 mmHg diastolic or greater than 160 mmHg systolic blood pressure was taken as indicating hypertension. This cut-off has been found to be of greater utility in identifying clinically significant hypertension in this setting than the lower values (e.g. 140/90) often used in high-income countries [25].

Additional background information was collected on all patients including post stroke medical care and motor and psychosocial function.

## **Statistics**

The data were quantitative in nature and collected at a nominal, ordinal and interval/ratio level. Data were analyzed using standard statistical software, *SPSS-17 for windows* (SPSS, Chicago, IL, USA). All variables were found to be non-normally distributed (Kolmogorov-Smirnov test) and so did not meet parametric assumptions. The data contained no outlier in any field (box-plot, stem-and-leaf analysis). Therefore, the Mann-Whitney U test (ordinal and interval/ratio data) or Pearson's chi-square test (categorical data) were used to characterise differences between patients and controls. Spearman's correlation test was used to assess associations between scores on standard ratings scales (HAD, WHOQOL-BREF, Barthel index). With dichotomous variables (e.g. gender) a point biserial correlation test was used.

## **Results**

Of 132 incident stroke cases identified from 15<sup>th</sup> June 2003 to 15<sup>th</sup> June 2006 (initial incidence study), [25] and 52 further cases identified between the end of the incidence study and 31<sup>st</sup> December 2007, 102 had died by the start of our study (1<sup>st</sup> June-30<sup>th</sup> September 2008). Sixteen cases declined to participate in a follow-up assessment citing co-morbidity or illness and 8 had left the study area or were otherwise unavailable for assessment. Therefore, 58 patients were assessed. There was no significant difference in age at stroke ( $U = 3114.5$ ,  $z = -1.608$ ,  $p = 0.108$ ) or gender ( $\chi^2 (1) = 0.047$ ,  $p = 0.828$ ) between those who were followed-up and those not followed-up. Patients were assessed at 0-66 months (mean 35.6 months, standard deviation 16.321) post-stroke, depending on the date of incident stroke.

### **Demographics**

The mean age of patients was 67.1 years (range 30-88, std dev. 13.923, 95% CI 63.53 to 70.75) and 28 (48.3%) were male. The mean age of controls was 61.7 years (range 27-86, std dev. 16.632, 95% CI 57.42 to 65.98) and 30 (51.7%) were male. Although controls were, on average, younger

than patients the difference was not significant ( $U = 1368.0$ ,  $z = -1.596$ ,  $p = 0.111$ ). Likewise, there was no significant difference in gender ( $\chi^2 (1) = 0.138$ ,  $p = 0.853$ ). Fifty-two patients were Christian and 5 were Muslim, one patient did not state a religion.

Two patients had had 1 previous stroke and 1 patient had had 2 previous strokes prior to the incident stroke. Of the remaining 55 patients with no previous strokes the average time since incident stroke was almost 3 years (34.8 months, range 9.3-60.7 months); for 31 patients more than 3 years had elapsed since their stroke, and for 16 more than 4 years had elapsed. Three patients had had a second stroke during the follow-up period (2 on the same side). Of the 53 patients who gave a response, 7 had had no education at all, 40 had been educated for 7 years or less at school (primary level) and 6 for up to eleven years (secondary level); none had progressed to tertiary education. Five patients were unable to give a response, due to dysphasia or aphasia, and the information was not known by a relative or carer. Those who had achieved higher levels of education were more likely to have attended hospital as an out-patient post-stroke ( $r = 0.325$ ,  $p = 0.015$ ) and to have received physiotherapy ( $0.266$ ,  $p = 0.044$ ). Moreover, these patients had less disability,  $r = 0.304$ ,  $p = 0.027$  (Barthel index) and lower levels of depression,  $r = -0.280$ ,  $p = 0.047$  (HAD scale).

Most patients lived in stone or brick built housing ( $n = 44$ ) and the median number of people per household was 5. The main form of income for 38 households was the sale of crops or livestock and was salaried employment for 9 households. Eleven households survived mainly on income from casual work. The median amount of land available for farming was 1.5 acres.

Twenty-nine patients were unable or unwilling to attend social gatherings (market, church etc), though only 2 did not have some form of contact with neighbours, relatives or friends at least once a week. Fifty-one patients (87.9%) had to give up work for a period of time after their stroke and, of these, 37 (72.5%) gave up work for more than 12 months, and 33 (64.7%) gave up work permanently. Those who were still employed, self-employed or working as a farmer at the time of

follow up (n = 18) were significantly younger ( $r = 0.346$ ,  $p = 0.08$ ) and had faster 10 metre walk test times ( $r = 0.369$ ,  $p = 0.015$ ) than those who were not employed.

Since their stroke 53 patients (91.4%) had had some form of medical care, with 29 having attended hospital as an out-patient, but only 4 admitted as an in-patient. Despite results showing that blood pressure was checked at least monthly in 41 patients and 34 (of 57 responses) were currently taking anti-hypertensives, 40 patients (69%) were hypertensive (using a cut-off of 160/90) on examination. Thirty-one patients had taken aspirin since their stroke, four patients were diabetic and 3 had suffered seizures since their stroke.

The motor function of patients is described in **Table 1**. Twenty seven of the 58 stroke patients scored less than the maximum 20 marks on the Barthel index. Seven patients were bed-bound, 4 chair-bound, 2 house-bound and 14 had limited mobility. The remaining 31 patients were physically independent. Twenty-one patients used a stick to walk, 2 used crutches, 1 used a Zimmer frame and 2 patients used a wheelchair for mobility.

For the 27 carers interviewed the average age was 47.0 years old, though the spread was broad (range 16-73, std dev. 15.989). Only 5 were male; 11 were a spouse or partner, 14 were a son or daughter (including in-laws) and 2 were a grand-daughter to the stroke survivor. Twenty-six carers lived with the patient, whilst the remaining carer lived within a few minutes' walk. Twelve carers had been looking after the patient for more than 4 years and a further six for more than 2 years. Seventeen carers were employed or self-employed and 4 were subsistence farmers.

### **Quality of life**

Six patients were unable to give responses to the WHOQOL-BREF, the HAD and the CSI-D due expressive dysphasia or complete aphasia. Of those who did participate five patients declined to answer question 21 (domain 3) as it enquired about how satisfied they were with the quality of their sex life, a sensitive issue particularly for elderly disabled patients in this culture. In addition one patient failed to give responses to questions 10 (Do you have enough energy for everyday life?) and

16 (how satisfied are you with your sleep?), both domain 1. No patient declined to answer more than two questions in any single domain, allowing a domain score to be calculated based on the questions that were answered, as described.<sup>25</sup> All 58 controls completed all sections of the WHOQOL-BREF.

A summary of patient and control scores for questions 1 and 2 and each of the four domains of the WHOQOL-BREF is shown in **Table 2**. QOL was significantly lower in stroke survivors than in controls across all domains. Gender, time elapsed since stroke and socioeconomic status were not associated with scores in any QOL domain. Older patients perceived poorer overall health ( $r = -0.301$ ,  $p = 0.032$ ) and had lower physical health with WHOQOL-BREF scores ( $r = -0.338$ ,  $p = 0.015$ ). **Table 3** summarises the influence of disability, power and motor function on each of the QOL domains. There was a significant association between lower levels of disability (Barthel index and modified Rankin score), better physical function (power and motor function) and higher WHOQOL-BREF physical health domain scores. Greater upper and lower limb power was also significantly associated with better quality of life in psychological and environment domains, but was not significantly correlated with social relationship domain related QOL.

A greater level of depression in patients was associated with lower WHOQOL-BREF physical domain ( $r = -0.422$ ,  $p = 0.002$ ), psychological health domain ( $r = -0.383$ ,  $p = 0.006$ ) and environment domain related QOL ( $r = -0.294$ ,  $p = 0.036$ ). Greater anxiety was found in patients with poorer physical health domain related QOL ( $r = -0.292$ ,  $p = 0.038$ ), psychological health domain related QOL ( $r = -0.321$ ,  $p = 0.022$ ) and poorer overall perception of QOL ( $r = -0.383$ ,  $p = 0.044$ ). Cognitive tests (CSI-D screening tool) showed no association between levels of cognitive functioning and QOL.

Patients who had had some form of medical care since their stroke had quicker 10 metre walk test times ( $r = -0.354$ ,  $p = 0.020$ ) and had higher WHOQOL-BREF physical health domain scores ( $r = 0.403$ ,  $p = 0.003$ ). Furthermore, patients who were taking anti-hypertensive drugs post-stroke had

higher WHOQOL-BREF psychological health domain ( $r = 0.481, p > 0.001$ ) and social relationships domain ( $r = 0.330, p = 0.018$ ) scores.

Better QOL was not significantly associated with the stroke survivor having more contact with their children, friends, family and neighbours. However, those who attended social gatherings more frequently had better QOL in physical domain ( $r = 0.490, p > 0.001$ ) and psychological health domain ( $r = 0.324, p = 0.019$ ) scores. They were, however, also less physically disabled, having quicker 10 metre walk test time ( $r = -0.511, p > 0.001$ ) and higher Barthel index ( $r = 0.625, p > 0.001$ ) scores.

### **Discussion**

This is the first published study of the long-term outcomes of incident stroke cases in SSA. QOL, as measured by the WHOQOL-BREF, was significantly lower in patients than controls in all four domains and in perceptions of overall QOL and overall health. Stroke survivor WHOQOL-BREF scores were broadly similar to those obtained for Nigerian stroke patients in a 2007 study [12].

In our study, time elapsed since stroke, gender and socioeconomic status were not associated with QOL in any domain, but age was significantly correlated with QOL in two domains. The association with age of scores in the physical health and overall health domains is perhaps unsurprising, and may be a function of age related change as much as stroke sequelae. However, the lack of correlation of age with other measures of QOL has been noted by other authors. Recent hospital-based Nigerian studies found little or no link between either age, gender or socioeconomic status and QOL [12,19,20]. Although two studies following up patients over a relatively short post-stroke period report a significant relationship between time elapsed since stroke and QOL [12,19], a study following up patients at least 6 months post stroke found no relationship between QOL and time elapsed since stroke [20]. This suggests that in SSA patient perceptions of QOL change little after the first six months post-stroke. Surprisingly, the cognitive function assessment score was not

associated with the patient WHOQOL-BREF score. This is in contrast to findings in a previous study of post-stroke African subjects [12]. Given the aetiology of stroke it may be expected that patients who have had a more severe stroke may have greater cognitive and physical impairment, and that this may impact negatively on QOL. The reasons for our findings to the contrary are likely to be complex and could be related to the inability of those with significant cognitive impairment to provide accurate information. Further study of this area is merited.

We found that there was a significant link between functional ability and QOL; similar results have been reported in previous developed world studies [4,8,33]. In a hospital-based Nigerian study health related QOL (overall and physical and psychological health) was predicted by modified Rankin score [19,34]. Our study provides a stronger insight into the specific functional limitation of stroke survivors and how this affects different aspects of QOL. All measures of motor performance, with the exception of sitting balance, were significant predictors of QOL in the physical health domain.

Improving access to rehabilitation services is likely to be important in optimising functional outcome after stroke [35]. We suggest that the provision of occupational and physiotherapy for stroke survivors in developing countries may help to reduce the impact of post-stroke disability on QOL. Skilled community nurses could train caregivers to deliver simple physiotherapy and use common household objects as occupational therapy aids [36].

High levels of anxiety and depression were correlated with lower scores in the physical and psychological health sections of the WHOQOL-BREF, and our results are similar to those found in studies in the developed world. A follow-up study in America found that 30% of survivors were depressed 1-3 years post stroke, with depression being the strongest predictor of overall psychological and health related QOL [8]. A Nigerian study also concluded that having psychiatric morbidity predicted reduced QOL in the physical, psychological and social relationships domains of the WHOQOL-BREF [12].

Greater awareness of the impact of anxiety and depression on stroke survivors in the developing world is needed if psychiatric morbidity is to be addressed and QOL optimised. Education of local healthcare workers regarding the psychological implications of stroke is important. Simple screening of stroke patients for anxiety and depression at a community level may then take place, thus enabling those in need of support to be targeted. A variety of health intervention strategies could be adopted for affected patients, including self help advice, the formation of stroke support groups, education of family members, community based counselling programmes and potentially the use of drug treatment for more severe cases.

A Swedish study found that contacts with close family members were sustained over the 3 year follow-up period, whereas contact with other relatives, friends and neighbours declined soon after stroke, and remained lower than for the general elderly population [9]. Similar findings were reported in a study in the Gambia, in which less than half of stroke-disabled patients attended social occasions, the mosque or church [16]. Involvement in family life was less hindered, with most survivors resuming caring roles and going to family ceremonies. Our study reveals that physical and psychological health related QOL is higher in stroke survivors who are able to attend social gatherings, but these patients also had lower levels of disability and greater motor function which are significant confounding factors. Thus, drawing firm conclusions on the role of social support in improving QOL is not possible. Nevertheless, the formation of stroke support groups may be a simple and inexpensive intervention that could improve patients' social interaction and self rated quality of life.

Although it is difficult to ignore the interplay between the various factors influencing QOL, physical health appears to be a key component of perceived QOL after stroke. It is likely to be a factor in helping to facilitate interaction in social situations, and may help to limit anxiety and depression.

Studies suggest that post stroke recovery is enhanced in patients who are admitted to stroke units [37]. Limitations of finance and infrastructure may prevent this from being feasible in some

developing world settings [38]. However, a co-ordinated community based protocol for providing physical rehabilitation, psychosocial support and low cost medical interventions could have a very positive impact on health outcomes and QOL of stroke survivors in SSA.

## **Conclusions**

Our findings highlight the significant burden that stroke poses on the QOL of the increasing number of survivors in SSA. The strongest correlates with QOL in stroke survivors are age, depression, anxiety, disability, motor function and involvement in social events. With the exception of age, these factors are potentially modifiable. Ideally, low cost community based rehabilitation and re-integration programmes should be offered to these patients in order to optimise their life satisfaction and functioning within society, and reduce the burden on caregivers. In addition, education of patients, families and the wider public on the long-term impacts of stroke may help to reduce the stigma around this condition and facilitate better community support [38]. This information could be widely disseminated to the population through healthcare settings, churches, mosques and schools, with particular care taken to respect local health beliefs [21]. We argue that investment in the rehabilitation of stroke survivors should be prioritised by policy makers in developing countries on a national level, given the poor quality of life experienced by stroke survivors [24]. When considering the funds needed to provide these services, one should take into account the cost to society from loss of productivity among disabled patients and their caregivers [39]. The numbers of first-ever strokes are predicted to rise exponentially over the next 20 years due to population ageing and demographic and epidemiological shifts [40]. The majority of these cases are likely to occur in the developing world. This will have a major impact on the work-force and family structure within these populations if prompt action is not taken to rehabilitate stroke survivors and optimise their QOL [19].

## **Limitations of this study**

The stroke incidence study paid for patients to attend hospital and receive treatment for the first year post-stroke. As such, the medical care received by the cohort may not be truly representative

of the wider stroke survivor population in rural Tanzania. Secondly, we were unable to carry out a pilot study to test the appropriateness of the wording and language used in the various sections of the study proforma. This gave rise to a number of communication problems, often arising through cultural differences. Furthermore, many of the study and control group struggled to rate their emotions, and physical and mental health status on a rating scale (HAD and WHOQOL-BREF scores). However, both of these scales have previously been used to assess post stroke survivors in SSA and the HAD has previously been validated in Nigeria [28]. Finally, visual problems were often uncorrected by glasses, or medical intervention, in our study cohort. This gave rise to a number of problems when visual interpretation of an image was required.

### **Key points**

- This is the first study in SSA to follow-up a cohort of incident stroke cases.
- QOL is lower in survivors at 1-5 years post-stroke than in age and sex-matched controls
- The strongest correlates with QOL in stroke survivors are age, depression, anxiety, disability, motor function and involvement in social events.
- If QOL in stroke survivors is to be improved, there is a need to ensure adequate community services and support are available.

**Acknowledgements:** We would like to thank all health-care workers, officials, carers and family members who helped in the identification of patients, the inputting of data and in the examination and assessment process. We would also like to acknowledge Professor Nigel Unwin and Professor George Alberti, who were part of the TSIP study group, for their helpful advice.

**Conflicting interests:** There were no conflicts of interest.

**Funding:** The Tanzanian stroke incidence study was funded by a grant from the Wellcome Trust, UK.

*Table 1. Motor function of stroke patients*

	Independent	Assistance of other required	Walking stick or frame required	Unable to assess
Bed mobility (rolling, bridging, lying sitting)	47	5	2	4
Sit to stand	37	5	9	7
Bed to chair	33	6	12	7
Chair to bed	33	6	12	7
Stairs	28	2	12	16
Outdoor mobility	32	6	11	9
Sitting balance	56	0	2	0
Standing balance	36	5	10	7
Gait and mobility	32	6	13	7

*Table 2. WHOQOL-BREF scores for patients and controls*

	WHOQOL 4-20	Range	Median	Significance
Question 1: How would you rate you quality of life?	Patient	1-5	3.0	U = 972.0, z = -3.539, p > 0.001
	Control	2-5	3.5	
Question 2: How satisfied are you with your health?	Patient	1-5	3.0	U = 867.5, z = -4.176, p > 0.001
	Control	2-5	4.0	
Domain 1: Physical health	Patient	7-17	11.0	U = 390.5, z = -6.740, p > 0.001
	Control	11-19	17.0	
Domain 2: Psychological health	Patient	9-17	13.0	U = 875.5, z = -3.836, p > 0.001
	Control	11-19	14.0	
Domain 3: Social relationships	Patient	5-20	13.0	U = 1100.5, z = -2.465, p = 0.013
	Control	9-20	16.0	
Domain 4: Environment	Patient	8-16	12.5	U = 909.0, z = -3.627, p > 0.001
	Control	10-17	14.0	

Patients n = 52, Controls n= 58; six patients were unable to give responses to the WHOQOL-BREF due expressive dysphasia or complete aphasia.

Table 3. Correlation between patient WHOQOL-BREF scores and neurological and motor function

		Spearman's test	WHOQOL Domain 1	WHOQOL Domain 2	WHOQOL Domain 3	WHOQOL Domain 4	WHOQOL Quality of Life	WHOQOL Health
<b>Disability</b>	Barthel index (n = 52)	Correlation	.451**	.127	-.062	.168	.117	.140
		Significance	.001	.370	.664	.233	.407	.321
	Modified Rankin scale (n = 52)	Correlation	-.471**	-.196	.029	-.284*	-.144	-.165
		Significance	.000	.163	.838	.041	.308	.241
<b>Power</b>	Upper limb <sup>a</sup> (n = 52)	Correlation	-.488**	-.371**	-.157	-.287*	-.197	-.083
		Significance	.000	.007	.265	.039	.161	.557
	Lower limb <sup>a</sup> (n = 52)	Correlation	-.505**	-.298*	-.181	-.409**	-.335*	-.115
		Significance	.000	.032	.199	.003	.015	.419
<b>Motor function</b>	General Mobility <sup>b</sup> (n = 52)	Correlation	.567**	.327*	.104	.316*	.346*	.188
		Significance	.000	.018	.463	.023	.012	.182
	Bed Mobility <sup>b</sup> (n = 52)	Correlation	-.360**	-.148	.103	-.173	-.242	.015
		Significance	.009	.294	.469	.219	.084	.918
	Bed to Chair <sup>b</sup> (n = 52)	Correlation	-.467**	-.206	-.040	-.166	-.266	-.188
		Significance	.000	.143	.776	.240	.057	.181
	Sit to Stand <sup>b</sup> (n = 52)	Correlation	-.493**	-.131	-.036	-.208	-.262	-.197
		Significance	.000	.354	.799	.138	.060	.160
	Stairs <sup>b</sup> (n = 52)	Correlation	-.546**	-.196	-.011	-.220	-.181	-.169
		Significance	.000	.163	.938	.117	.198	.231
	Outdoor Mobility <sup>b</sup> (n = 52)	Correlation	-.442**	-.266	-.076	-.235	-.241	-.166
		Significance	.001	.056	.594	.094	.085	.239
	Standing balance <sup>b</sup> (n = 52)	Correlation	-.498**	-.169	.003	-.216	-.262	-.197
		Significance	.000	.231	.982	.124	.061	.162
	Gait and Mobility <sup>b</sup> (n = 52)	Correlation	-.465**	-.244	-.088	-.180	-.248	-.186
		Significance	.001	.081	.534	.202	.076	.186
	Able to walk 10 metres (n = 42)	Correlation	-.374**	-.115	-.130	-.253	-.065	-.070
		Significance	.006	.418	.357	.070	.649	.620
	10 metre walk test time (seconds) (n = 42)	Correlation	-.272	-.212	-.075	-.137	-.135	-.306*
		Significance	.082	.178	.637	.387	.393	.048

Six patients were unable to give responses to the WHOQOL-BREF, HAD and CSI-D due to expressive dysphasia or complete aphasia, 16 patients were unable to undertake the 10 meter walk test due to physical impairment.

\*Significant at  $p \leq 0.05$  level

\*\*Significant at  $p \leq 0.01$  level

<sup>a</sup> 0 normal, 1 MRC grade 4+, 2 MRC grade 4, 3 MRC grade 3, 4 MRC grade 1-2, 5 no movement<sup>31</sup>

<sup>b</sup> 0 Independent, 1 Verbal prompts, 2 Assistance of one, 3 Assistance of two, 4 Aid required, 5 Unable.

## References

1. Johnston SC, Mendis S, Mathers CD (2009) Global variation in stroke burden and mortality: estimates from monitoring, surveillance, and modelling. *Lancet Neurol* 8:345-354.
2. WHO Burden of Disease Study Group (2004) The global burden of disease, 2004 update. Geneva, Switzerland: World Health Organization.
3. Feigin VL (2007) Stroke in developing countries: can the epidemic be stopped and outcomes improved? *Lancet Neurol* 6:94-97.
4. Carod-Artal J, Egido JA, Gonzalez JL, Varela de Seijas E (2000) Quality of life among stroke survivors evaluated 1 year after stroke: experience of a stroke unit. *Stroke* 31:2995-3000.
5. Paul SL, Sturm JW, Dewey HM, Donnan GA, Macdonell RA, Thrift AG (2005) Long-term outcome in the North East Melbourne Stroke Incidence Study: predictors of quality of life at 5 years after stroke. *Stroke* 36:2082-2086.
6. Niemi ML, Laaksonen R, Kotila M, Waltimo O (1988) Quality of Life 4 Years after Stroke. *Stroke* 19:1101-1107.
7. Edwards JD, Koehoorn M, Boyd LA, Levy AR (2010) Is health-related quality of life improving after stroke? A comparison of health utilities indices among Canadians with stroke between 1996 and 2005. *Stroke* 41:996-1000.
8. King RB (1996) Quality of life after stroke. *Stroke* 27:1467-1472.
9. Astrom M, Adolfsson R, Asplund K, Astrom T (1992) Life before and after Stroke - Living-Conditions and Life Satisfaction in Relation to a General Elderly Population. *Cerebrovascular Dis* 2:28-34.
10. Granger CV, Hamilton BB, Gresham GE (1988) The Stroke Rehabilitation Outcome Study .1. General Description. *Arch Phys Med Rehabil* 69:506-509.
11. Viitanen M, Fugl-Meyer KS, Bernspang B, Fugl-Meyer AR (1988) Life Satisfaction in Long-Term Survivors after Stroke. *Scand J Rehabil Med* ;20:17-24.
12. Fatoye FO, Komolafe MA, Eegunranti BA, Adewuya AO, Mosaku SK, Fatoye GK (2007) Cognitive impairment and quality of life among stroke survivors in Nigeria. *Psychol Rep* 100:876-882.
13. O'Donnell MJ, Xavier D, Liu L, Zhang H, Chin SL, Rao-Melacini P, et al (2010) Risk factors for ischaemic and intracerebral haemorrhagic stroke in 22 countries (the INTERSTROKE study): a case-control study. *Lancet* 376:112-123.
14. Connor MD, Walker R, Modi G, Warlow CP (2007) Burden of stroke in black populations in sub-Saharan Africa. *Lancet Neurol* 6:269-278.
15. Brainin M, Teuschl Y, Kalra L (2007) Acute treatment and long-term management of stroke in developing countries. *Lancet Neurol* 6:553-561.
16. Garbusinski JM, van der Sande MA, Bartholome EJ, Dramaix M, Gaye A, Coleman R, et al (2005) Stroke presentation and outcome in developing countries: a prospective study in the Gambia. *Stroke* 36:1388-1393.
17. Ming L, Bo W (2007) Stroke in China: epidemiology, prevention, and management strategies. *Lancet Neurol* 6:456-464.
18. Nicoletti A, Sofia V, Giuffrida S, Bartoloni A, Bartalesi F, Lo Bartolo ML, et al (2000) Prevalence of stroke - A door-to-door survey in rural Bolivia. *Stroke* 31:882-885.
19. Owolabi MO (2008) Determinants of health-related quality of life in Nigerian stroke survivors. *Trans R Soc Trop Med Hyg* 102:1219-1225.
20. Akinpelu AO, Gbiri CA (2009) Quality of life of stroke survivors and apparently healthy individuals in south-western Nigeria. *Physiother Theory Pract* 25:14-20.
21. Mshana G, Hampshire K, Panter-Brick C, Walker R (2008) Urban-rural contrasts in explanatory models and treatment-seeking behaviours for stroke in Tanzania. *J Biosoc Sci* 40:35-52.
22. Hackett ML, Duncan JR, Anderson CS, Broad JB, Bonita R (2000) Health-related quality of life among long-term survivors of stroke - Results from the Auckland Stroke Study, 1991-1992. *Stroke* 31:440-447.

23. Walker RW, Rolfe M, Kelly PJ, George MO, James OF (2003) Mortality and recovery after stroke in the Gambia. *Stroke* 34:1604-1609.
24. Fitzgerald SM, Srikanth VK, Evans RG, Thrift AG (2008) Benefits and Challenges in Stroke Research in Developing Countries. *Brain Impairment* 9:198-204.
25. Walker R, Whiting D, Unwin N, Mugusi F, Swai M, Aris E, et al (2010) Stroke incidence in rural and urban Tanzania: a prospective, community-based study. *Lancet Neurol* 9:786-792.
26. The WHOQOL Group (1998) Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine* 28:551-558.
27. Zigmond AS, Snaith RP (1983) The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 67:361-370.
28. Abiodun OA (1994) A validity study of the Hospital Anxiety and Depression Scale in general hospital units and a community sample in Nigeria. *Br J Psychiatry* 165:669-672.
29. Hall KS, Hendrie HC, Brittain HM, Norton JA, Rodgers DD, Prince CS, et al (1993) The Development of a Dementia Screening Interview in 2 Distinct Languages. *Int J Methods Psychiatr Res* 3:1-28.
30. Mahoney FI, Barthel D (1965) Functional evaluation: The Barthel Index. *Maryland State Med J* 14:56-61.
31. Bonita R, Beaglehole R (1988) Modification of Rankin Scale: Recovery of motor function after stroke. *Stroke* 19:1497-1500.
32. Medical Research Council (1975) Aids to the investigation of peripheral nerve injuries. London: HMSO.
33. Astrom M, Asplund K, Astrom T (1992) Psychosocial Function and Life Satisfaction after Stroke. *Stroke* 23:527-31.
34. Owolabi MO, Ogunniyi A (2009) Profile of health-related quality of life in Nigerian stroke survivors. *Eur J Neurol* 16:54-62.
35. Minelli C, Fen LF, Minelli DP (2007) Stroke incidence, prognosis, 30-day, and 1-year case fatality rates in Matao, Brazil: a population-based prospective study. *Stroke* 38:2906-2911.
36. Garbusinski JM, van der Sande MAB, Bartholome EJ, Dramaix M, Gaye A, Coleman R, et al (2005) Stroke presentation and outcome in developing countries - A prospective study in The Gambia. *Stroke* 36:1388-1393.
37. Phillips SJ, Eskes GA, Gubitz GJ (2002) Description and evaluation of an acute stroke unit. *CMAJ* 167:655-660.
38. Lemogoum D, Degaute JP, Bovet P (2005) Stroke prevention, treatment, and rehabilitation in sub-saharan Africa. *Am J Prev Med* 29:95-101.39. Hochstenbach J. (2000) Rehabilitation is more than functional recovery. *Disabil Rehabil* 22:201-204.
40. Strong K, Mathers C, Bonita R (2007) Preventing stroke: saving lives around the world. *Lancet Neurol* 6:182-187.