

Functioning at 6 months post stroke following discharge from inpatient rehabilitation

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Objectives. To determine activity limitations, participation restrictions, health-related quality of life and caregiver strain in community-dwelling stroke survivors discharged from an intensive inpatient rehabilitation programme at 6 months post stroke.

Methods. Fifty-one consecutive stroke patients admitted to a Western Cape rehabilitation centre were included. Community-dwelling participants ($N=46$) at 6 months post stroke were assessed using the Modified Rankin Scale (MRS), Barthel index (BI), Nottingham extended activities of daily living (NEADL) scale, Euroqol (EQ-5D) instrument and caregiver strain index (CSI).

Results. Most participants (73.9%) were independent in activities of daily living or had minimal disability (BI 75 - 100). However, according to the NEADL, many participants were not independent in housework (60.9%), food preparation (52.2%), shopping (80.4%)

and public transport use (65.2%), implying the need for caregiver assistance. According to the MRS, 29% of participants were severely disabled, requiring caregiver assistance for basic needs, and 20% could not be left alone. Feelings of anxiety or depression were felt in 50% of participants and 59% reported pain or discomfort, according to the EQ-5D. High levels of caregiver strain were reported in 56% of caregivers (CSI). Follow-up after discharge was reported in few participants.

Conclusions. Consideration should be given to support for stroke survivors and caregivers after discharge and whether targeted programmes can improve specific aspects of functioning, such as community mobility.

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Stroke is a major cause of death in South Africa (SA) and the incidence is increasing.¹ Many patients survive the initial event but are left with disability and face the challenge of reintegrating into residential and community living.^{2,3}

Little information is available on stroke survivor functioning in SA, particularly at the level of activity limitation (difficulties in task execution) and participation restriction (problems experienced in involvement in life situations).⁴ A study in a deprived rural community reported a higher prevalence of stroke survivor disability than expected on the basis of international studies.⁵ In another study of patients discharged from a remote rural hospital, 60% had a Modified Rankin Scale (MRS) score of 0 - 3 at 3 months and participation in work, social activities, housework and sport was reduced.⁶ Patients receiving rehabilitation at community healthcare centres (CHCC) in the Western Cape experienced problems with extended activities of daily living (ADL) and community integration.⁷ These studies refer to stroke cohorts receiving little rehabilitation input. There are few data on the outcomes of patients who are able to access intensive inpatient rehabilitation in SA.⁸

We aimed to determine the activity limitations and participation restrictions, health-related quality of life and caregiver strain in survivors discharged from an inpatient rehabilitation facility at 6 months post stroke.

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Methods

This study was part of a larger, longitudinal and descriptive study that drew from the methodology of the European Collaborative Evaluation of Rehabilitation in Stroke across Europe (CERISE) project. CERISE included a multi-centre comparison between stroke rehabilitation units in Europe.⁹ In our study, consecutive stroke patients were recruited between June 2005 and March 2006 from the Western Cape Rehabilitation Centre (WCRC), a regional specialist centre offering inpatient interdisciplinary rehabilitation. Inclusion criteria were: (i) first-ever stroke according to the World Health Organization definition of 'rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or leading to death, with no apparent cause other than vascular origin';¹⁰ (ii) admission to the WCRC within 3 months post stroke; (iii) 18 - 85 years of age; (iv) living within 50 km of the WCRC. Patients were excluded if they had pre-stroke neurological conditions.

Outcome measures in terms of stroke disability were: ADL independence according to the Barthel index (BI);¹¹ abilities for community living according to the Nottingham extended activities of daily living (NEADL) scale;^{7,9,12} and global disability according to the Modified Rankin Scale (MRS) structured interview.^{13,14} Responses to individual questions on the MRS structured interview were used to describe perceived changes in usual duties and activities - including work, family responsibilities, social and leisure activities - and relationships with family and friends. Health-related quality of life was assessed with the Euroqol (EQ-5D) instrument,¹⁵ and the caregiver strain index (CSI)¹⁶ was used to determine levels of caregiver strain.

The NEADL, CSI and MRS were translated into Afrikaans and Xhosa and back-translated, before a consensus version was produced. Reliability testing of the translated instruments was conducted on a small group of 1 - 6 patients using a test-retest methodology; although no statistical analysis was possible (small sample size), no major cultural or environmental issues were identified that invalidated their use. Patients living in the community were assessed at 6 months post stroke using the BI, NEADL, EQ-5D, CSI and MRS. Participants with severe cognitive or language deficits were excluded from EQ-5D analysis. Proxies were not asked to respond on the respondents' behalf to avoid introducing bias.¹⁷

Onset to admission interval and length of stay in the rehabilitation centre were documented, as well as post-discharge contact with health services for follow-up (occupational, physio-, speech and language therapy, social work, and medical or nursing assistance).

Assessments were conducted by the researcher (SR) in English or Afrikaans, and in isiXhosa with the assistance of a translator. Unmet clinical needs, identified by the researcher, were referred to the appropriate services. The Ethics Committee of the University of Cape Town approved the study. Descriptive statistics were used to represent the data.

Results

Eligibility criteria were met by 59 patients; 1 refused consent, and 7 could not give informed consent due to cognitive or language deficits

Table 1. Participant characteristics

Age (years)	
Range	21 - 80
Mean ± SD	51.9±14.3
Gender (n)	
Men	20
Women	26
Side of lesion (clinical assessment), n (%)	
Right	18 (39.1)
Left	26 (56.5)
Bilateral	2 (4.3)
Type of stroke, n (%)	
Haemorrhagic	9 (19.6)
Ischaemic	16 (34.8)
Indeterminate*	21 (45.7)
BI on admission	
Range	10 - 100
Median (IQR)	50 (35 - 65)
Severity at admission (Barthel ADL index[†]), n (%)	
Severe (0 - 45)	22 (47.8)
Moderate (50 - 70)	15 (32.6)
Mild (75 - 95)	7 (15.2)
None (100)	2 (4.3)
Housing type (%)	
Formal	87
Informal	13
Housing characteristics (%)	
No running water	11
No indoor toilet	24
No shower or bath facilities	26
No electricity	4
Characteristics of rehabilitation stay	
Admitted within 30 days of stroke onset (%)	78
Mean time between stroke onset and admission (days)	23±21
Average length of stay (days)	62±28
Follow-up after discharge, n (%)	
Re-admitted for further rehabilitation	4 (8.7)
Received >6 outpatient therapy sessions [‡]	4 (8.7)
No contact with health services	5 (10.9)

*Type of stroke considered indeterminate if no magnetic resonance image (MRI) or computed tomography (CT) results available.

[†]According to classification of Wade and Langton Hewer.¹⁹

[‡]Includes physiotherapy, occupational therapy and speech and language therapy.

Table 2. Participants who performed items on the NEADL independently

	Participants (N=46) n (%)
Mobility	
Walk outside	32 (69.6)
Get in and out of car	32 (69.6)
Walk over uneven ground	27 (58.7)
Cross roads	25 (54.3)
Climb stairs	18 (39.1)
Travel on public transport	16 (34.8)
Household	
Feed yourself	46 (100.0)
Make a hot drink	29 (63.0)
Take hot drink from one room to another	28 (60.9)
Manage own money when out	28 (60.9)
Wash up	26 (56.5)
Make a hot snack	22 (47.8)
Wash small items of clothing	19 (41.3)
Do own housework	18 (39.1)
Wash a full load of clothes	13 (28.3)
Own shopping	9 (19.6)
Leisure	
Use telephone	37 (80.4)
Read newspaper/book	33 (71.7)
Manage own garden	12 (26.1)
Go out socially	12 (26.1)
Write letter	8 (17.4)
Drive a car	2 (4.3)

(next of kin could not be reached). Fifty-one were registered; 1 died, 1 was institutionalised, 1 could not be contacted, 1 declined consent, and 1 repeatedly did not arrive for scheduled assessments. Forty-six patients were thus assessed in the community at 6 months post stroke.

The mean interval of onset to admission was 23±21 days; most (78.2%) participants gained admission to rehabilitation within 30 days of stroke. Mean length of stay in rehabilitation was 62±28 days. Many participants did not have any substantial follow-up after discharge (Table 1).

Fig. 1 shows the percentage of participants needing help with individual items of the BI at 6 months. Fourteen participants (30.4%) were independent for all items (BI=100) and 20 (43.5%) had mild disability (BI=75 - 95). The median BI was 90 (IQR 70 - 100).

Table 2 outlines the number and percentage of the cohort who performed NEADL activities independently. MRS scores (Table 3) indicated that 20% (n=9) of participants had severe disability (MRS=5) and the need for constant caregiver availability; 9% (n=4) could be left alone but needed assistance with basic needs such as toileting, hygiene and eating (MRS=4); half the participants (n=23) had moderate disability (MRS=3); 17% (n=8) could look after their own affairs but were not able to participate in all usual activities/roles (MRS=2); and 4% (n=2) experienced no significant disability and could carry out all previous activities and duties (MRS=1). No participants were free of symptoms (MRS=0).

Table 3. Scores according to the Modified Rankin Scale

MRS	Description	Participants (N=46) n (%)
5	Severe disability: requires constant caregiver	9 (20)
4	Needs assistance with basic needs but can be left alone	4 (9)
3	Moderate disability: independent in basic self-care, but needs assistance with meal preparation, housework, shopping, financial management or travel	23 (50)
2	Able to look after own affairs, not able to participate in all usual activities/roles	8 (17)
1	No significant disability: able to carry out all previous activities/duties	2 (4)
0	No symptoms	0 (0)

Table 4. Participants reporting changes in role since stroke according to the MRS structured interview responses (N=46)

	Unable n (%)	Reduced ability n (%)	No change n (%)	Not a previous role n (%)
Leisure and social life	7 (15.2)	31 (67.4)	7 (15.2)	1 (2.2)
Family responsibilities	14 (30.4)	13 (28.3)	3 (6.52)	16 (34.8)
Work/seeking work	18 (39.1)	10 (21.7)	2 (4.3)	16 (34.8)

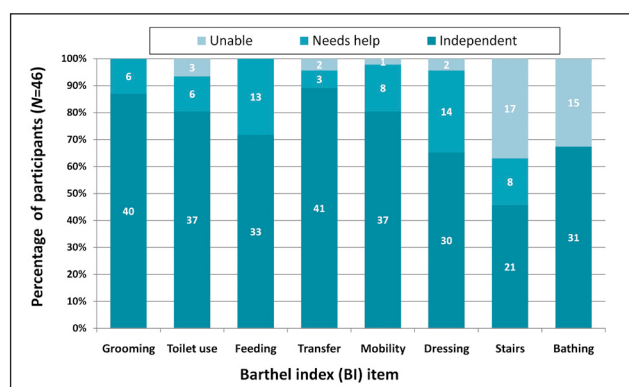


Fig. 1. Percentage of participants (N=46) needing help with individual items of the Barthel index at 6 months. Mobility categories of 'walks with help of one person' and 'wheelchair independent' have been condensed into 'needs help'. Transfer categories of 'major help' and 'minor help' have been condensed into 'needs help'.

In individual responses to questions addressing change in role (Table 4), 82.6%, 60.8% and 58.7% reported that they were unable, or had a reduced ability, to participate in social and leisure activities, work activities and family responsibilities, respectively. A further 37% reported problems with relationships or feelings of isolation.

Two participants with severe language or cognitive deficits were excluded from the EQ-5D follow-up. Included participants (N=44) reported problems in all quality of life domains, with the least problems reported in self-care (30%). Ability to perform usual activities (61%) was the most affected – 27% reported severe problems, 59% reported pain or discomfort, 50% reported feelings of anxiety or depression, and 52% reported problems with mobility. Visual analogue scores of perceived health state ranged from 30 to 100, with a median of 70.0 (IQR 57 - 85).

Data were available for the caregivers of 41 patients; 1 participant did not need a caregiver, and 4 caregivers failed to return the questionnaires. Fifty-six per cent of caregivers had CSI scores ≥ 7 , reflecting high levels of strain.¹⁸ Financial strain (65.9%) and work adjustments (53.6%) featured prominently.

Discussion

Stroke survivors undergoing intensive inpatient rehabilitation at a regional specialist centre in the Western Cape were studied. Their young average age was striking; persons of this age would be expected to be economically active and have dependents to support. Moreover, participants were largely from a low income bracket.

ADL outcomes were favourable with 73.9% of patients independent in ADL or having minimal disability, defined by BI scores of 75 - 100.¹⁹ Thirty per cent of participants had a BI score of 100 at 6 months compared with 20% of stroke survivors in the CHCC cohort receiving less intensive rehabilitation.⁷ Moreover, the median BI of 90 at 6 months in our study is similar to European stroke units in the CERISE study (median range 85 - 100).²⁰ However, differences in age and severity profiles between cohorts are likely to complicate comparisons. Assistance was mostly required for stair-climbing, dressing and bathing – as in local and international studies.^{2,7}

Although most participants were independent in ADL, results of the NEADL showed that many required assistance with instrumental activities required for living at home, such as preparing hot drinks and snacks, washing up, washing clothes and doing the housework. This implies a burden of care on family members and, for some, constitutes a loss of role.

According to the NEADL, few participants had independently participated in activities outside the home, such as doing their own shopping and going out unassisted socially.

In terms of travel ability, 34.8% had used public transport and 69.6% had walked outside and got in and out of a car. However, given the low average income, few participants would own cars, making inability to travel by public transport particularly serious. Stroke survivors experience difficulties in using public transport in SA.^{7,8} Independent functional walking within the community is another common difficulty, owing to residual impairments. Although 80% of all participants could walk independently indoors (mobility item in the BI), this does not imply ability to achieve safe walking in the community. Few participants had performed the more demanding items of crossing roads (54.3%), walking over uneven ground (58.7%) or climbing stairs (39.1%). Difficulties in community mobility are exacerbated by environmental barriers such

as unfavourable terrain and local public transport that are not geared to persons with disability. The NEADL identifies actual performance rather than ability and does not distinguish between limitations of innate disability and environmental restrictions. Dependence for community mobility increases the burden on caregivers and limits opportunities for community participation. The lack of suitable and affordable public transport for persons with stroke, impacts the access to participation in activities outside the home and to healthcare. Transport for persons with disabilities must be addressed at government level.

Three features of the MRS results warrant highlighting: (i) severe disability (MRS of 4 or 5) was experienced by 29% of stroke survivors, with 20% requiring a caregiver, typically a family member, to be present at all times; (ii) about half of the participants were independent in essential ADL but required assistance from family members to sustain community living (MRS=3); and (iii) a high proportion reported a loss of role including many with only mild levels of disability.

Visual analogue scores pertaining to health-related quality of life on the EQ-5D were similar to those of the CERISE project (median of 70 v. 60 - 70 in the European centres).²⁰ It is clinically important that 59% of participants reported pain and discomfort and 50% reported feelings of anxiety and depression, as these are potentially modifiable.

The caregiver strain of 58% was similar to that of another study at the same facility, but was higher than in international studies.⁸ Stroke survivors in developed countries received more therapies, nursing services, contact with doctors and psychologists after discharge, and severe stroke patients were more likely to be institutionalised at 6 months after stroke.²⁰ Because SA has few suitable residential facilities, patients with severe disabilities are discharged into the care of families, often without support and follow-up.⁸ Lack of community support services and financial pressures contribute to higher caregiver strain and to a double loss of income as family members must give up work to care for the stroke survivor.⁸

Levels of community participation reflect environmental factors and the level of impairment of the stroke patient. Given their low incomes, lack of financial resources is an additional barrier to functioning. Furthermore, low-cost housing features such as outdoor toilets (23%) and no running water inside (11%) affect the complexity of ADL for tasks such as toileting, and extended ADL such as washing up and food preparation.

In terms of rehabilitation, most participants were admitted within 30 days of stroke and length of hospital stay was similar to or longer than that of international studies.⁹ However, participants received little input after discharge and 10% had no further contact with healthcare services. Consequently, potentially modifiable problems such as pain and depression were not identified and support of patients and caregivers over the transition after discharge was lacking. Intervention after discharge improves performance in extended ADL and community mobility.^{20,21}

Four (8.7%) participants were re-admitted for a second rehabilitation stay to optimise functioning. While the study did not permit further analysis, short re-admissions at a later stage of recovery

may facilitate reintegration and improved community participation; the cost-and-benefit thereof requires further investigation. Resources limit what can be provided realistically in the healthcare system of SA; research is needed to identify interventions in the community after discharge that can make a difference at the least cost, identify patients most likely to benefit, and assess whether targeted programmes may improve specific aspects of functioning.

As the study reported functioning in stroke survivors admitted to a single rehabilitation unit in Cape Town, care should be taken with generalising the results.

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