



Community-based care of stroke patients in a rural African setting

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Background. To develop a community-based model of stroke care, we assessed discharge planning of stroke patients, available resources and continuity of care between hospital and community in a remote rural setting in South Africa. We sought to determine outcomes, family participation and support needs, and implementation of secondary prevention strategies.

Methods. Thirty consecutive stroke patients from the local hospital were assessed clinically (including Barthel index and modified Rankin scores) at time of discharge and re-assessed 3 months after discharge in their homes by a trained field worker using a structured questionnaire.

Results. Two-thirds of all families received no stroke education before discharge. At discharge, 27 (90%) were either bed- or chair-bound. All patients were discharged into family care

as there was no stroke rehabilitation facility available to the community. Of the 30 patients recruited, 20 (66.7%) were alive at 3 months, 9 (30%) had died, and 1 was lost to follow-up. At 3 months, 55% of the remaining cohort were independently mobile compared with 10% at discharge. Of the 20 surviving patients, 13 (65%) were visited by home-based carers. Only 45% reported taking aspirin at 3 months.

Conclusions. The 3-month mortality rate was high. Most survivors improved functionally but were left with significant disability. Measures to improve family education and the level of home-based care can be introduced in a model of stroke care attempting to reduce carer strain and reduce the degree of functional disability in rural stroke patients.

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Stroke remains a leading cause of death and adult disability in the developing world. The Global Burden of Disease study indicates that 80% of stroke deaths occur in low- and middle-income regions.¹ Based on death registration statistics, stroke is the most common cause of death among people >50 years old in South Africa² and represents the dominant type of vascular disease in sub-Saharan Africa.³ In this region, all-stroke fatality from available hospital-based prospective studies is about 30% at 1 month, which is much higher than the 20% in much older populations in the rest of the world.⁴

In African countries, health is linked to overall development and socio-economic standing. South Africa is undergoing rapid urbanisation associated with a change in the risk environment. Sub-Saharan Africa faces the huge burden of the HIV/AIDS pandemic. Infectious diseases and perinatal and nutritional disease dominate the causes of death in Africa, compared with non-communicable diseases in high-income countries. However, the burden of stroke and other vascular diseases will probably increase substantially in Africa, with

health transitions in line with changing social, economic and demographic structures. Because of wide socio-economic disparities, diseases of poverty and the emerging non-communicable diseases related to lifestyle are likely to overlap and persist for a long time, posing an additional burden to health care systems in the region. HIV infection contributes to an increased risk of stroke, which has been attributed to a number of factors including opportunistic infections. HIV-associated vasculopathy is also recognised and may be contributing to stroke prevalence in younger patients.⁵

Resources for stroke care and rehabilitation are deficient in developing countries, particularly in rural areas. Patients with acute stroke are often discharged from hospital without an option of receiving adequate rehabilitation by trained health care professionals. An adaptable cost-effective approach to community-based stroke management is needed for patients after their discharge from hospital.

We undertook a multi-centre longitudinal cohort study in two urban, one semi-rural, and one rural site, to develop a community-based model for stroke care in South Africa. Ingwavuma in northern KwaZulu-Natal was selected as a suitable remote rural site. The community of around 116 000 is spread over an area with a radius of about 80 km and is served by a single local district health facility – Mosvold Hospital. We aimed to assess discharge planning of stroke patients and to evaluate integration and continuity of stroke care between hospital and community. We sought to determine outcomes, family participation and support needs, and implementation of secondary prevention strategies. To provide context for our data, we characterised the demographic profile of the population in this region, and assessed the hospital and

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community resources available to stroke patients in the area and the availability of patient education programmes at this site. Our focus was on the structure and function of the home-based care (HBC) system.

Methods

Demographic profile and assessment of resources

Demographic information on the size, age distribution, gender, employment status and education level of the Ingwavuma population (which falls under Jozini Municipality) was obtained from online reports from the Department of Statistics website, based on the 2001 national census.⁶ Additional data concerning income levels, water and electricity supply, sanitation and dwelling structures were taken from the same source. The internal annual report of Mosvold Hospital for the year 2006 - 2007 (Dlamini: unpublished data, 2007) gave the number of patients seen at the hospital, their length of stay, and the staffing and resources available at the facility. Data regarding antenatal HIV prevalence, average life expectancy and causes of death were obtained from the South African Department of Health National HIV and Syphilis Sero-Prevalence Survey⁷ and from a local mortality study.⁸

Information on HBC services in the area was obtained from the Ingwavuma Orphan Care Annual Report 2006 - 2007.⁹ To determine whether or not the HBC services available to the local community during the study were consistent with those stated in the most recent annual report, author SW interviewed the director of the organisation, 2 nurses and 3 trained home-based carers actively involved in service provision. Information was obtained on the structure and staffing of the service, the training of home-based carers, case selection and criteria for visits, the specific services provided by home-based carers, the frequency and duration of visits, transportation issues, and the clinical spectrum of cases seen.

Hospital recruitment

Consecutive stroke patients from the local hospital were recruited and followed up from February 2007 to January 2008. Eligibility criteria included any patient with a clinical diagnosis of stroke, who was alive at the time of discharge after a stay in hospital. Written informed consent was obtained from patients or their caregivers before enrolment. Patients were assessed at the time of discharge by SW. Hospital assessment was implemented using a standardised questionnaire including risk factors for stroke, neurological deficits, secondary prevention strategies, discharge functioning, family education, discharge destination and planned follow-up. The 10-item modified Barthel index¹⁰ and modified Rankin score¹¹ were used as assessment scales in recruitment. The modified Barthel index assesses the ability to perform daily living activities on a scale of 0 (complete dependence on help with daily living activities) to 20 (independence). The modified Rankin score is a measure of disability with scores ranging from 0 (no symptoms at all) to

6 (death); a score of 5 indicates severe disability (the patient is bedridden and incontinent and requires constant nursing and attention).

Three-month follow-up

Patients were assessed 3 months after discharge in their homes by a trained field worker using a standardised structured questionnaire. The field worker was employed in the hospital's rehabilitation therapy department and is well known and accepted within the local community. She was trained by SW on the use of the questionnaire, interview techniques and the assessment scales, which also included a Carer Strain Index.¹² The Carer Strain Index assesses the severity of the physical, financial, emotional, social and overall burden on the carer on a scale that ranges from 5 (no burden) to 25 (severe burden). The follow-up questionnaire evaluated outcomes, secondary prevention advice and compliance, access to community-based services, family participation and caregiver strain. Stroke patients were asked to rate their own level of involvement in activities (work, social, housework, community and sporting activities) before and after their stroke, using a simple 5-point score scale.

Results

Demographic profile

The population of Jozini Municipality was 184 049; 57% were women and 43% men; 59% were <20 years old. Most deaths in the community are certified at the local hospital mortuary, although many individuals are born without official registration and buried without death certification. The average age at death of those certified at Mosvold Hospital in 2006 was 39.1 years for men and 41.7 years for women. There are no reliable data on HIV prevalence in the community, but the HIV rate among antenatal clinic attendees in the health district was 39.8% in 2007, when most adult deaths certified at the hospital were HIV-related.

In the municipal area, 11% of households derived their lighting from electricity; 85.6% used candles as a primary light source; 74.3% used wood as a fuel for cooking. Piped water was supplied directly to 2.7% of households, and 34.1% fetched their water from an open water source. Of households with access to piped water, 52.2% had to walk further than 200 metres to collect it from a communal source. Over 53% of dwellings were classified as traditional (Fig. 1). There were no toilet facilities in 62.3% of households, and over half of those with some type of facility used pit latrines.

The unemployment rate in the district among working-age men was 56.6%, and 63.8% among women; 80.8% employed men and 80.2% women earned a monthly income <R3 200 (equivalent to US\$320); 54% of all females and 45.7% of males >20 years old in the region had no education. Of people between 5 and 24 years old, 24.4% had never attended any educational facility.



Fig. 1. Typical traditional dwellings in the area of the study.

Hospital services

The local hospital supported 10 peripheral primary level clinics and mobile teams covering 30 clinic points. There were 6 wards with a total of 246 beds. In 2007, there were 13 doctors at the hospital, and 59 of 107 professional nursing posts were filled. The rehabilitation therapy department included 4 physiotherapists, an occupational therapist, a speech therapist and a dietician. Two social workers were based at the hospital. This staff complement was responsible for managing 49 000 outpatients annually (156/day) and admitting 9 400 patients per year (783/month), whose average stay was 7 days. Basic radiography and ultrasound were available at the hospital, but no CT scanner or other neuroimaging was available on site. The nearest referral facility with a CT scanner was 3 hours' drive away.

Hospital assessment

A total of 30 patients (6 males and 24 females) were recruited at this site. The mean age was 68.6 years; 5 (16.7%) were <50 years; 95% of those >60 years relied on an old-age pension as their main source of income; 16.7% had no income at all at the time of their stroke. About half the cohort had spent an average of 7 years at school, while the balance had no formal education (Table I). Risk factors for stroke included hypertension (80%), diabetes (13%), smoking (17%), and previous strokes/transient ischaemic attacks (TIAs) (17%). Three (10%) patients were HIV-positive. Only 4 (13.3%) patients had computed tomography (CT) brain scans. According to clinical assessment at the time of discharge, 15 (50%) patients with a mean age of 70 years had large-vessel (atherothrombo-embolic) disease, 7 (23%) lacunar infarcts (mean age 64 years), 5 (17%) haemorrhagic strokes (mean age 82 years), 2 (6.7%) HIV-associated infarcts (mean age 32 years), and 1 patient with suspected cardio-embolic stroke (age 87 years).

Discharge planning

Most patients presented late, with a mean delay of almost 2 days from onset of symptoms to presentation at hospital. The average duration of hospital stay was 6 days. All the patients

Table I. Demographic profiles (N=30)

Gender	
Male	6 (20%)
Female	24 (80%)
Mean age	68.6 years
Marital status	
Married	10 (33.3%)
Widowed	17 (56.5%)
Education	
No schooling	16 (53.3%)
Average school years	9
Income	
Pension	21 (70%)
Household income <R1 000 (≈\$100)	15 (75%)
Living conditions*	
Unserviced shack	16 (80%)
Average number of persons per household	6

*Of those followed up.

were discharged into family care as there was no stroke rehabilitation facility. Two-thirds of all families did not receive any stroke education on or before discharge. Of followed-up patients, 80% lived in traditional dwellings with no water or electricity, and 75% shared a household income of <R1 000 (US\$100) per month with an average of 6 people (all patients had a total household income <R5 000 (US\$500)/month).

Access to community-based services

No regular stroke education sessions were provided for the community at the hospital or its 10 peripheral clinics. Several organisations in the area provide a variety of services, mostly focusing on poverty and AIDS. Ingwavuma Orphan Care (IOC) is an NGO started by a British doctor in 2001 to care for AIDS orphans in the community; it now provides HBC for the population of the area. While IOC's main focus remains caring for people with HIV-related illnesses, it provides support to patients with other chronic conditions, including stroke. In 2007, IOC employed 3 nurses and 45 home-based carers who made a total of 80 visits a month. Although they received no specific stroke care training, carers provided services such as general health education and nursing care, and delivery of drugs and other supplies. Each carer travelled about 7 km each day on foot or bicycle to conduct home visits. A total of 13 (65%) of our patients were visited by home-based carers at some point in the 3 months after discharge. Nine patients were visited by a physiotherapist, and 2 were able to consult a social worker during this period.

Outcomes

Of the 30 recruited patients, 20 (67%) were alive at 3 months, 9 (30%) had died and 1 was lost to follow-up. Those who died had a higher mean age (77.3 v. 64.2 years) and had lower Barthel indices on average (1.9 v. 5.2) at the time of discharge from hospital. At discharge, the average Barthel index for



all patients was 4, and the majority (93%) had severe Rankin scores in the range 4 - 5; only 2 (6.7%) were able to toilet, transfer, and mobilise independently, and 27 (90%) were either bedridden or chair-bound; 26 (86.7%) were considered by their families to be completely independent before the stroke. Two of the 4 patients who were not completely independent before the index stroke died within 3 months of discharge from hospital.

At the 3-month follow-up, Rankin scores for survivors improved, with 12 (60%) patients having scores of 0 - 3 compared with only 2 (10%) falling into this range at the time of discharge (Fig. 2). This trend is also reflected by improvement in the Barthel indices: at follow-up, the average Barthel index for survivors was 14 compared with 5 at the time of discharge. Patients also showed improvement in specific activities: at 3 months, 12 survivors were independently mobile compared with 2 at discharge; 15 were transferring independently compared with 2 at discharge; 5 were bedridden or chair-bound compared with 18 at discharge; and 11 were toileting independently compared with 2 at discharge (Fig. 3).

Eight surviving patients (40%) still had severe Rankin scores (range 4 - 5) at 3 months; 17 (56.7%) of all patients had severe Rankin scores or had died within 3 months of discharge (i.e. Rankin scores 4 - 6). The self-assessment scores reflecting participation in activities after stroke were reduced in each category: work, social, housework, community and sporting activities (Fig. 4).

Compliance with secondary prevention strategies

At the follow-up visit, all patients claimed to be taking their prescribed antihypertensive medication but 11 (55%) of those who had been prescribed aspirin admitted to defaulting.

Family participation and caregiver strain

The average age of primary caregivers to the surviving patients was 43.7 years, with 20% younger than 30 years; 18 (90%) of the primary caregivers were female (5 spouses, 4 daughters or daughters-in-law, 5 granddaughters, 2 sisters, 2 mothers, 1 neighbour, and 1 patient had no caregiver). The unemployment rate among caregivers in our cohort was almost 80%. The mean Carer Strain Index (CSI) score was 17 in the moderately severe range (4 of the caregivers who were interviewed had severe scores, 9 had moderately severe scores, 2 had moderate scores, and 2 had mild scores).

Discussion

The demographic and socio-economic profile of our cohort reflects that of the community living in and around Ingwavuma. Many aspects of their lives are defined by high levels of poverty and unemployment, low levels of education, large family units and poor access to basic resources. Only 1 patient was lost to follow-up. Although our cohort was small, the high 3-month mortality is similar to the all-stroke case

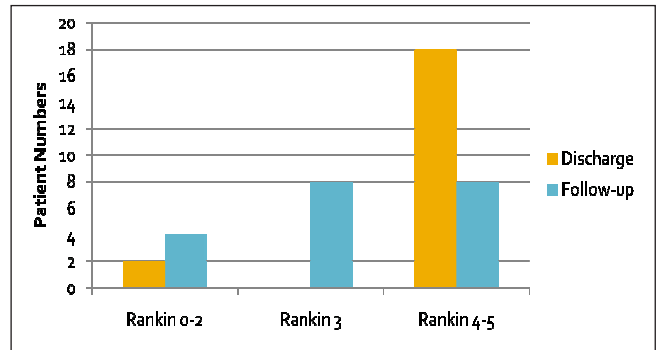


Fig. 2. A comparison of modified Rankin scores of the survivors at time of discharge from hospital and at 3-month follow-up.

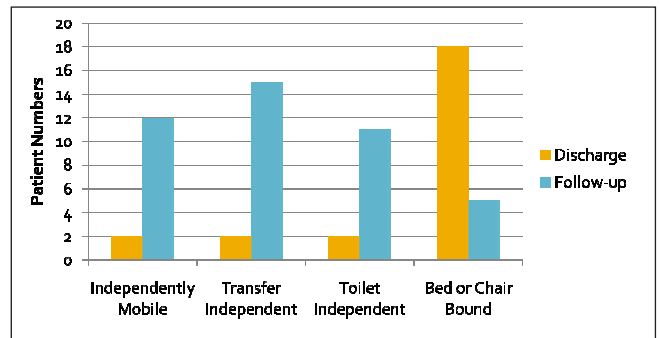


Fig. 3. A comparison of functional ability of the survivors at time of discharge from hospital and at 3-month follow-up.

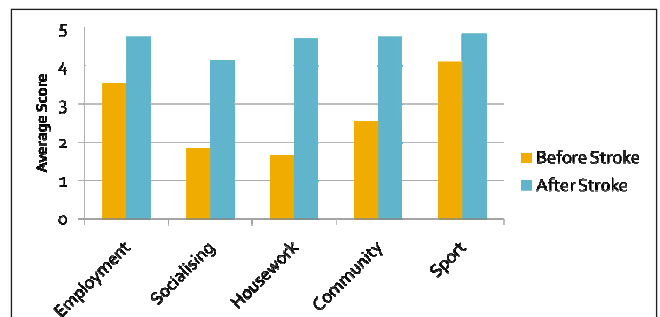


Fig. 4. Self-assessment scores of survivors before and at 3 months after stroke. 1 = a lot; 5 = not at all.

fatality (from hospital-based studies in developing countries⁴) of about 30% at 1 month. Our stroke mortality at 3 months would have been higher had we included all in-patient stroke deaths, but these data were not recorded. The 10 patients who died during community follow-up tended to be older, with lower Barthel scores on discharge.

Hypertension was by far the most important and prevalent risk factor for stroke, which is consistent with others who have identified hypertension as the most powerful predictor for stroke in sub-Saharan Africa.¹³ Despite growing prevalence, awareness of the condition remains low¹⁴ but, in some rural settings, community education sessions on hypertension and stroke have been shown to be effective in contributing towards stroke prevention in the community.¹⁵ Our patients' claims of



being compliant on their antihypertensives were interpreted with caution as the fieldworker did not check prescriptions or count drugs. The low levels of compliance on aspirin were probably indicative of general medication default rates, and we recommend that this issue be addressed in any proposed model of community-based stroke care.

Most of our patients had severe disabilities that, at the time of discharge, required assistance with daily living activities from another person, and that represented significant changes from their pre-morbid function, as almost all of them were completely independent before the index stroke. Two-thirds of patients or their caregivers did not receive any stroke care training or secondary prevention education on or before discharge from hospital; this issue must be addressed in any future model of community-based stroke care.

At 3 months, 17 (56.7%) of our 30 patients had either died or were severely disabled, and 80% of survivors were left with moderate or severe disability (modified Rankin score 3 - 5); this compares unfavourably with a larger urban population-based study in India, in which 38.5% of stroke survivors were moderately to severely disabled at 28 days based on Rankin scores.¹⁶ Factors such as the size of our sample and the selection bias of the study (e.g. long delays in presenting to hospital after stroke, more severe strokes admitted and milder strokes less likely to present or be admitted to hospital) limit conclusions regarding poor outcomes and deaths. Nevertheless, most survivors in our cohort had significant functional improvement at 3 months, with improved average Barthel indices and Rankin scores compared with discharge. When questioned about specific tasks, most survivors showed improvement in their ability to walk, transfer and toilet independently, commensurate with improvement in the overall indices.

Although our patients showed functional improvement in certain crucial areas, stroke had a significant impact on their lifestyle. The self-assessment responses indicated that their ability to participate in important cultural and social activities after stroke was substantially impaired. High patient-dependency levels and poor family support are predictors of adverse outcomes in caregivers, which could be improved by caregiver training.¹⁷ The lack of a stroke rehabilitation facility, as well as inadequate home-based support (only 65% of patients were visited by home-based carers) and high levels of poverty contributed towards the high levels of caregiver strain. In our study, the burden of stroke rested most heavily upon women in terms of the stroke patient and the caregiver.

Any model of community-based stroke care in rural South African settings should include a system of stroke education for caregivers and patients, and should implement structures that strengthen the level of HBC and training. Awareness of stroke and cardiovascular risk factors (particularly

hypertension) needs to be fostered by improved community education. Nurse practitioners and home-based carers could play an important role in checking blood pressure and monitoring treatment and compliance after discharge from hospital. In-service training of rural-based health care professionals in the protocols of acute stroke management could also reduce in-hospital complications, morbidity and mortality, providing optimum potential for improved outcomes following discharge into the community. Without adequate numbers of health workers available for rehabilitation in such communities, caregivers are the most likely candidates to adopt this surrogate role, and could be trained to be more active in the rehabilitation process. While poverty and gender inequality remain long-term problems in health care, these simple interventions can improve stroke outcomes and relieve caregiver strain in rural settings such as Ingwavuma.

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References

1. Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJL. Global and regional burden of disease and risk factors, 2001: systematic analysis of population health data. *Lancet* 2006; 367: 1747-1757.
2. Statistics South Africa. *Mortality and Causes of Death in South Africa 2005: Findings from Death Notification*. Statistical Release P0309.3. Pretoria: Statistics South Africa, 2007.
3. Reddy KS. Cardiovascular disease in non-Western countries. *N Engl J Med* 2004; 350: 2438-2440.
4. Connor MD, Walker R, Modi G, Warlow CP. Burden of stroke in black populations in Sub-Saharan Africa. *Lancet Neurology* 2007; 6: 269-278.
5. Tipping B, de Villiers L, Wainwright H, Candy S, Bryer A. Stroke in patients with human immunodeficiency virus infection. *JNNP* 2007; 78: 1320-1324.
6. Statistics South Africa. Census 2001. www.statssa.gov.za/census01 (accessed 25 September 2008).
7. Department of Health. *National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2007; 2008*. www.doh.gov.za/docs/antenatal-f.html (accessed 25 September 2008).
8. Vaughan Williams CH. Analysis of impact of HIV/AIDS on deaths certified at Mosvold Hospital, Ingwavuma, Northern KwaZulu-Natal from 2003 to 2006. *SA Fam Pract* 2007; 49: 16a-e.
9. Ingwavuma Orphan Care Annual Report 2006-7. IOC medical records. www.orphancare.org.za (accessed 25 September 2008).
10. Colin C, Wade DT, Davies S, Horne V. Barthel ADL Index: a reliability study. *Int Disabil Stud* 1988; 10: 61-63.
11. Van Sweiten JC, Koudstaal PJ, Visser MC, Schouten HJ, van Gijn J. Interobserver agreement for the assessment of handicap in stroke patients. *Stroke* 1988; 19: 604-607.
12. UK Alzheimer's Association. Carer Strain Index. www.glosppccag.nhs.uk/userfiles/docstore/pdf/carers%20strain%20index.doc (accessed 13 January 2009).
13. Lemogoum D, Degate J, Bovet P. Stroke prevention, treatment, and rehabilitation in sub-Saharan Africa. *Am J Prev Med* 2005; 29: 95-101.
14. Mensah GA. Epidemiology of stroke and high blood pressure in Africa. *Heart* 2008; 94: 697-705.
15. Iso H, Shimamoto T, Naito Y, et al. Effects of a long-term hypertension control program on stroke incidence and prevalence in a rural community in northeastern Japan. *Stroke* 1998; 29: 1510-1518.
16. Dalal PM, Malik S, Bhattacharjee M, et al. Population-based stroke survey in Mumbai, India: Incidence and 28-day case fatality. *Neuroepidemiology* 2008; 31(4): 254-261.
17. McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke* 2005; 36: 2181-2186.