# A survey of the long term outcome of elderly stroke survivors and the needs of their carers

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A survey was conducted to assess the long term outcome of 60 elderly stroke survivors (mean age, 81.7 years). Of these patients, 48% died within one year of discharge and 79% of the mortality occurred in the first six months. Patients discharged to institutions after the initial stroke had a significantly higher risk of death in one year (relative risk = 1.47) compared with those who were discharged home. For those who survived for a mean period of 18.6 months, 72% (21/29) were institutionalised. This group had significantly worse functional status and mobility compared with those who were living at home. The caring of elderly stroke patients was considered a heavy burden for most carers at home or in institutions and the need for medical and social support was great.

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#### Introduction

Stroke is the third leading cause of death in Hong Kong<sup>1</sup> and is one of the most important causes of chronic morbidity and handicap among the elderly.<sup>2</sup> Older stroke patients have been shown to have higher institutionalisation rates and a greater decline in functional ability during long term follow up.<sup>3</sup> Local data on the long term outcomes of elderly stroke survivors are scarce. While an earlier study<sup>4</sup> involved younger stroke patients, a recent study<sup>5</sup> assessed stroke survivors with a mean age of approximately 70 years. The survival, disability, and place of residence at three and 20 months after stroke were assessed, but the carers were not evaluated. The present survey was carried out to obtain further information on the outcome and the caring burden of elderly stroke survivors.

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#### Methods

The survey was carried out in mid-1995 by the Department of Geriatrics, Tuen Mun Hospital, Tuen Mun. There are two acute intake wards (34 beds each) for 24-hour emergency admission under the department. All patients aged 80 years or older or those already followed up by the Geriatric Specialist Clinic (irrespective of age, usually those older than 65 years) requiring emergency admission were admitted to the geriatric wards. A departmental stroke registry was established in August 1993 and all stroke patients admitted under the care of the department were recorded. Eighty-nine patients with admission dates from August 1993 to April 1994 were identified. During this period, the average duration of hospital stay for stroke patients was 15.3 days and 18 patients died during the hospitalisation (mortality rate, 20%).6

Of the remainder (71) who were alive on discharge, 60 could be traced or contacted by telephone and form the sample of this study. Stroke patients received standard medical, nursing, and rehabilitative in-patient treatment in an acute ward setting. There was no established setting for prolonged rehabilitation such as a rehabilitation ward or geriatric day hospital in the

region during this period. Most patients were followed up in the Geriatric Specialist outpatient clinics after discharge. Only those patients who could tolerate long distance travel were referred to geriatric day hospitals in other regions for further rehabilitation after discharge.

Table 1. The relationship between premorbid placement and the initial placement on discharge after stroke\*

	Discharge to home	Discharge to institution
Premorbid placement living at home	: 16	19
Premorbid placement living in institution	: 1	19

P<0.01 (Chi-square test with Yate's correction)
\* data incomplete for five patients

A structured telephone interview was carried out by three nursing staff who were experienced in community geriatrics. The carer and/or the patient were interviewed. The patient's physical state, functional state, and the carer's perceived burden were assessed.

The statistical methods used for analysis included: Student's *t* test for normal continuous variables, Chisquare test and Fisher's Exact test for dichotomous data with Yate's correction for 2 x 2 contingency table, and the Mann-Whitney U test for comparing ordinal measurements.

#### Results

For the 60 elderly stroke survivors who were discharged alive the mean age was 81.7 years; one patient aged 62 years was referred from our community service while the age range of the remainder was 71-98 years. There was a significant association between the pre-morbid place of living of patients and their placement on discharge after stroke (Table 1). Most patients who were institutionalised in the premorbid stage returned to live in institutions. More than half of those living at home in the premorbid stage were discharged to institutions. The mean time lag between the hospital discharge and the survey was 18.6 months (range, 15 - 23 months).

## Mortality

Forty-eight per cent of those discharged died within one year of discharge and 79% of this group died within the first six months. A comparison of the characteristics of the survivors and non-survivors one year after discharge is shown in Table 2. Those discharged to an institution after surviving the initial stroke had a significantly higher mortality rate at one year compared with those who were initially discharged home (P<0.05,  $\chi^2$  test). The relative risk of mortality in the first year after discharge to an institution versus home was 1.47 (95% CI, 1.04-2.06). There was no difference in the premorbid placement, mean age, and computed tomography brain finding between the two groups.

## Institutionalisation

Thirty-one stroke patients were alive one year post-discharge. At the time of the survey, two more had died (at 18 and 20 months, post-discharge). Thus, only 29 patients had their functional level and their carers' burden assessed (Table 3). The mean post-discharge period for these patients was 18 months (15-21 months). Twentyeight per cent (8/29) were living at home and all were discharged home after the initial hospitalisation. Of the 72% (21/29) living in institutions, 24% (5/21) were initially sent home on discharge but were subsequently placed in institutions. Institutionalised patients had significantly worse Katz<sup>7</sup> activities of daily living (ADL) scores, Lawton<sup>8</sup> instrumental activities of daily living (IADL) scores, and mobility, compared with those living at home. A significant proportion of carers felt that there was a moderate to severe burden in taking care of the stroke patient. Fifty per cent of carers at home and 38% of carers in institutions expressed the need for nursing and/or professional support and placement arrangement.

## Discussion

The present study is limited by the relatively small sample size and its partially retrospective nature. Some important information such as functional status on discharge and concomitant illnesses in stroke survivors were incomplete. Both have been found to influence the long term functional status and disability of stroke patients<sup>9-11</sup> and could be important confounding factors in explaining our results. Our survey shows that the long term prognosis of elderly stroke survivors is poor. A high mortality occurs in the first few months after discharge. The mortality rate of 48% in one year is comparable to previous local findings. The exact causes of death could not be traced. Woo et al<sup>12</sup> describe a mortality rate of 29% in the first three months and a further 19% by 20 months for a younger cohort of mean

Table 2. Comparison of survivors and non-survivors one year post-stroke

At 1 year post-stroke	Non-survivor	Survivor	P value
No.	29	31	
Mean age (y)	82.2	80.7	ns
Premorbid placement:			
Home	16	23	$ns^*$
Institution	12	8	
Discharge destination after stroke	<b>:</b> :		
Home	4	13	
Institution	23	18	$P=0.048^{\dagger}$
Unknown	2	0	
CT brain finding:			
Haemorrhage	6	3	
Infarct or normal	21	21	ns
Unknown	2	7	

<sup>\*</sup> data incomplete for one patient; † P=0.048 (Home vs Institution) [Chi-square test with Yate's correction]; RR=1.47 (95% CI, 1.04-2.06); ns not significant

age 69 years. In the same study, it was also found that factors predicting long term mortality were, in order of importance: old age, history of ischaemic heart disease, low mental-test score, low serum cholesterol concentration, low Glasgow Coma Score on admission, and the presence of left ventricular hypertrophy.

In our survey, most long term survivors were institutionalised. The institutionalisation rate of 72% in one year is high compared with another local study<sup>5</sup> that describes an institutionalisation rate of 17% by 20 months. This is probably related to the older age of our cohort. In addition, five of 13 patients initially discharged home were institutionalised at one year. The reasons for the change in placement could not be deduced from the telephone interview. However, a decline in patient functional status with carer breakdown is the most likely cause. It has been found that factors such as physical disability, mental disability, and marital status (absence of spouse) are associated with an increased chance of institutionalisation.<sup>13</sup> Three of the carers/patients living in institutions voiced the need for a change of placement and 18/21 of carers reported variable degrees of perceived burden. These patients belonged to the institutionalised group with low mean ADL scores of 1.8 and IADL scores of 0.6. Despite the use of different functional scales, the disability level is apparently comparable with the infirmary patients reviewed by Au Yeung et al (mean Barthel score of 29/100, mobility

score of 5.1/9.0). A majority of these patients were already placed in either private or subvented Care and Attention homes. It seems that the level of care in these institutions cannot cater for the needs of these severely disabled elderly stroke patients. Most of the carers, both at home and in institutions, asked for nursing or professional support besides placement change. This reflects the need for intensive nursing care and frequent medical advice. These cannot be provided by the existing community services, even with the support of on-demand medical outpatient consultation. Thus, the demand for infirmary beds for elderly stroke survivors in Hong Kong is considerable.

The relatively short stay in hospital and the suboptimal post-discharge rehabilitation service offered to this cohort of elderly stroke patients during the study period might contribute to the poor outcome. Organised rehabilitation, such as a stroke unit or geriatric day hospital, has been shown to improve mortality and morbidity and to reduce the need to institutionalise stroke patients. 15,16 With the establishment of a geriatric day hospital service and the Community Geriatric Assessment Team in our region, a better outcome for stroke patients is expected.

## Conclusion

Elderly stroke survivors experience a high mortality

Table 3. Comparison of the health status and carer burden associated with long term survivors living at home and in institutions

Patient placement at the time of interview	Living at home	Living in institution	P value
No.	8	21	
Initial discharge after hospitalisation:			
Home	8	5	P=0.0003
Institution	0	16	
Mean age (y)	77.8	80.9	ns
CT brain finding:			
Haemorrhage	2	1	ns
Infarct or normal	5	14	
Unknown	1	6	
Mean ADL score <sup>7</sup> (0-6)	4	1.8	P=0.06
Mean IADL score <sup>8</sup> (0-8)	3.3	0.6	P=0.003
Ambulation:			
Walker (Outdoor or home-bound)	7	5	P=0.007
Non-walker (Bed or chair-bound)	1	13	
Unknown	0	3	
Carer's perceived burden:			
Mild (score 1-2)	5	11	ns
Moderate (score 3)	3	4	
Severe (score 4-5)	0	3	
Unknown	0	3	
Support required:			
Placement	1	3	ns
Nursing/professional support	3	5	
Financial support	0	0	
Psychological support	0	0	
Others/unknown	4	13	

ns not significant

rate in the first year after the event, especially in the first few months. For the long term survivors, the institutionalisation rate is high. The survivor's physical disability imposes a considerable burden on the carers, both at home and in institutions. This echoes the geriatrician's reminder: "Hospital admission is just the first chapter in stroke care." Health care planners should remember the post-hospitalisation phase of any disabling illness in the elderly such as stroke when planning the distribution of resources.

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