Long-term outcome after discharge from a stroke rehabilitation unit

ABSTRACT—The evidence is compelling that stroke units are effective when compared to management of patients on general medical wards. However, the evidence remains equivocal that better outcome is sustained in the longer term. This paper reports an investigation of cognitive and emotional outcome, environmental consequences, social activities, and physical outcome in 57 consecutive one-year survivors of a stroke discharged from a stroke and neurological rehabilitation unit. Satisfaction with inpatient and outpatient services was also investigated. Results were compared with previously reported studies of long-term outcome after stroke.

Mean Barthel activities of daily living score at one year or more post-stroke was 16.8. Arm function was impaired in 43% of the participants in the study. Nearly half had cognitive and emotional problems, 19% communication problems, and 25% problems with access both inside and outside their house. All but four of the one-year survivors were less active after their stroke than before. More than 40% were dissatisfied with at least one aspect of inpatient and/or outpatient services.

The long-term consequences of stroke in all areas investigated were considerable and in line with previous reports. Some suggestions for reducing these effects are made, including better information for patients about stroke and rehabilitation, improved access to psychology services, detailed assessment prior to hospital discharge of the patient's living environment and effective coordination with social services to improve access to their living environment.

Various studies have compared management of stroke patients by a specialist multidisciplinary team with their management on general medical or neurology wards. An overview of 10 such trials indicated that management of stroke patients by a specialist team was associated with lower mortality rates [1]. Functional gains in patients managed by a stroke team have also been demonstrated [2–5]. However, these studies did not investigate possible reduction in social activities, cognitive and emotional outcome, or environmental consequences following stroke. The present study has

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RICHARD LANGTON HEWER, FRCP, Professor of Neurology, Stroke Research Unit, Frenchay Hospital, Bristol specifically examined these factors as well as physical outcome in stroke patients discharged from a stroke and neurological rehabilitation unit. We also assessed levels of satisfaction with services provided. Our results are compared with those of previously published studies of long-term outcome after stroke.

The Lime Tree Rehabilitation Unit (LTRU)

LTRU is part of Frenchay Hospital, a 540 bedded general district hospital. The unit is mixed-sex and comprises 16 beds—10 for stroke and six for other neurological diseases. The rehabilitation team consisted of doctors, nurses, social workers, occupational and speech therapists, physiotherapists, a leisure coordinator and helper. Patients were encouraged to use their free time as beneficially as possible. This involved them in carrying out exercises on the ward and participating in both individual and group leisure activities.

Subjects

During the first 16 months following the opening of LTRU (in October 1992), 103 stroke patients were admitted for rehabilitation. Twenty-three patients were excluded from the current study, six because their stroke occurred more than one month prior to hospital admission, one because she had moved away, and 19 patients had died by one year. The remaining 77 patients were invited to participate in this study, and 57 (74%) agreed. Seven subarachnoid haemorrhage (SAH) patients were included in the study.

The characteristics of the patients who participated in the current study are given in Table 1, together with those of the total stroke patient population managed on the LTRU between October 1992 and October 1994 (163 patients). Statistical tests [6] were performed to determine whether the participants in the current study differed from the total population of LTRU stroke patients with respect to: age, sex, type of stroke, side of initial weakness, activities of daily living (Barthel score) [7,8] on admission to and discharge from the unit, and discharge destination. No significant differences were found for any of these variables (see Table 1).

The majority of participants (63%) were living with their partners before the stroke, 13 (23%) were living alone and a few with a child (4), sibling (2) or friend (1). Seven (12%) moved following their stroke: three to a nursing home, one to a residential home, and one

Patient characteristic	Participating subjects (n=57)		Total LTRU stroke population (n=163)		Statistical tests and significance
	number	%	number	%	
Sex:					
male	31	54.4	94	57.7	Binomial test $p = 0.34$ NS
female	26	45.6	69	42.3	2ormai cese, p = 0.54, 145
Age:					
mean	66	SD: 11.2	66		t-test $t = 0.013$ NS
range	31-86				DF = 56
Type of stroke:					
infarct	36	63.2	113	69 3	v^{2} -test $v^{2} = 1.01$ NS
ICH	11	19.3	26	16.0	χ -test, χ = 1.01, NS
SAH	7	12.3	14	8.6	
brainstem/cerebellar	3	5.3	10	6.1	
Side of weakness:					
left	26	45.6	68	41 7	Binomial test n = 0.22 Nish
right	23	40.4	78	47.9	Binomial test, $p = 0.22$, N3 ⁵
bilateral	1	1.8	3	1.8	
none	7	12.3	13	8.0*	
Barthel ADL score: initial:					
mean	10.5		. 10.9	t-test $t = 0.64$ NS	
median	9				DE = 52
range	2-20 (n=53)				
discharge:					
mean	16		15.6		
median	17				t-test, $t = 0.81$, NS
range	5–20 (n=52)				DF=51
Discharge destination:					
alone	10	17.5	33	20.8	χ^{2} -test, $\chi^{2} = 0.42$, NS
not alone	39	68.4	105	66.5	DF=2 ^c
nursing home	4	7.0	8	5.1	
residential home			3	1.9	
hospital	4	7.0	9	5.7**	

Table 1. Comparison of patients who participated in the current study with the total population of stroke patients admitted to the Lime Tree Rehabilitation Unit between October 1992 and October 1994

ADL = activities of daily living ICH = intra-cerebral haemorrhage SAH = subarachnoid haemorrhage

DF = degrees of freedom

a infarct, JCH and others [brainstem/cerebellar, SAH] b

left, right only C

private address alone, private address not alone, others [nursing home, residential home, hospital

was transferred from LTRU to another hospital and was still an inpatient 14 months later. Two participants moved house, but continued to live independently.

Assessments

Participants were assessed, using the tests and questionnaires given below, 12-28 months after discharge from LTRU by an independent observer (HCD), who had no intrinsic commitment to obtain a better or worse outcome score. All participants were visited at home to assess their post-stroke functioning within their own living environment.

Physical functioning:

Arm function: Frenchay Arm Test (FAT) [9].

NS = not significant

- Walking: structured question about walking outside the home.
- Falls: structured question about frequency of falls.
- Sleep: the subjects were asked whether problems were experienced with sleep (yes/no).

Activities of daily living

Activities of daily living (ADL) were assessed using the Barthel Index (BI) [7,8].

Cognition

Memory: the story recall (both immediate and delayed) subtest of the Adult Memory and Information Processing Battery (AMIPB) [10] was administered. This test contains norms for adults up to 75 years of age.

Attention: a recent study on cognitive impairments found that, three months post-stroke, a cancellation task produced the highest failure rate (38.5%) [11]. A digit cancellation task was therefore included to assess attentional deficits [12]. Both number of errors and completion time were recorded.

Visuoperceptual abilities: during the initial phase of the study, copying a Greek cross was used as a measure of visuo-perceptual abilities, but very few subjects had any difficulty with this task. Later subjects were additionally asked to copy the complex two-dimensional shape used in the figure recall subtest of the AMIPB [10].

Language: the full version of the Frenchay Aphasia Screening Test (FAST) was used, assessing comprehension, expression, reading and writing [13].

Emotional functioning

Hospital anxiety and depression scale (HAD) [14]: a score of 1–7 is considered normal, 8–10 borderline abnormal, and 11–18 abnormal. This scale was originally designed for application within hospital, but has been used outside a hospital setting [15].

Living environment

Access was recorded to the bedroom, toilet, bathroom, and outside (garden and beyond). Questions were also asked about the use of a commode and the consequences of the stroke on the subject's economic self-sufficiency.

Activities: the Frenchay activities index (FAI) [16,17] questionnaire assessed the frequency of domestic, leisure, work and outdoor activities. Both the current situation and the situation immediately prior to the stroke were recorded. The post-stroke FAI was recalculated as a percentage of the pre-stroke score, to take into account the pre-stroke level of activities.

Satisfaction with stroke services

The Hospsat (concerned with stroke services in hospital) and Homesat (concerned with stroke services in the community) [18] statements were used. Respondents are asked to indicate on a four-point scale whether they agree with each statement. A total score can be calculated for both subscales separately. The Hospsat ranges from 0–24 and the Homesat from 0–15. The higher the score, the greater the satisfaction with the services. These questionnaires, and also the HAD questionnaire, were sent to the participants approximately one week before the home visit. They were asked to complete them before the visit.

Literature search

Studies for comparison were obtained through a literature search using the CD-ROM version of the Medline database available for the period from 1990 to April 1995. Additional papers were found through the bibliographies of those reports. To ensure studies were comparable to the current study, only those which concerned hospital-based stroke populations and reporting outcome 1–3 years after onset of stroke were included.

Results and comparison with previous studies

Tables 2 and 3 show the results of the various tests in this study, together with those found in previous studies.

Activities of daily living

There was impairment of ADL in approximately twothirds of the subjects: almost half were mildly disabled (BI score: 15–19) [40] and about one-fifth moderately to severely disabled (BI: 5–14) (mean BI: 16.84). A randomised controlled trial of rehabilitation in a specialist stroke unit reported similar findings (mean BI: 16.94) one year after a stroke [5]. Lower scores (BI: 14.48) were attained in patients who had been managed on general medical wards.

Cognitive impairments

Nearly half (45.9%) of the subjects had one or more cognitive impairments, the most frequent being visuoperceptual and attentional deficits (Table 2). No other studies have investigated attentional impairments (other than neglect) *one year* after stroke. However, a previous study did show that at *three months* post-stroke, 38.5% of patients scored below the fifth percentile on a task similar to that used in the current study (in which 27% were impaired) [11]. About 19% of subjects failed the FAST (Table 2). The only other study which satisfied our criteria reported a similar proportion (18%) of long-term stroke survivors suffering from aphasia [27].

Emotional consequences of stroke

With respect to the emotional consequences of stroke, 37.5% scored borderline or abnormal on the depression subscale of the HAD and about 40% on the anxiety subscale (Table 2), with 28 (53.8%) scoring borderline or abnormal on at least one of the two subscales. Previous studies varied widely in the reported percentage of stroke survivors with depression at 1–3 Table 2. Number (%) of subjects in the current and previous studies with problems in physical functions, activities of daily living (ADL), cognitive and emotional functions, activities, access in their living environment and finances

	Current study		Previous studies		
Droblem	No.	04 with problem	04 with problem	Deferre	
	assesseu	% with problem	% with problem	References	
Physical function:			and a second second second second		
arm function	56	43	41-45	19	
mobility outdoors	56	61	41 (unable)	20	
		(not independent	20	21	
		without aid)	70 (approx)	22	
falls	56	55	58	23	
				(<1 year	
	C1	24	10.20	post-stroke)	
sleep	21	24	10-30	24	
ADL skills:					
walking	56	34	22–28	3, 4	
toileting	56	13	24-60	3, 4, 22	
dressing	56	36	19–60	3, 4, 22	
eating	56	36	1–60	3, 4, 22	
Cognitive function:					
memory:					
immediate recall	40	10	31	25	
delayed recall	40	5	A has also been been and		
attention	48	27	39	11 (<1 year post-stroke)	
visuo-perceptual					
function	32	25	41-74	25, 26	
language	53	19	18	27	
Emotional					
consequences:					
depression	52	38	12–51	28–35	
anxiety	52 .	40	36-46	33	
Activities:					
no longer working	13*	77	42-83	20, 25, 36–37	
			86	38	
			(age <60 years)		
unable to return					
to driving	36**	78	81	20	
overall level of					
activities (FAI)	55	93			
Access:					
bedroom	56	16			
toilet	56	20			
bathroom	56	18			
outdoors	56	30			
garden	53	28			
Finances:	52	33			

number working before stroke

number driving before stroke

FAI = Frenchay Activities Index

years poststroke (12-51%). Anxiety has been investigated less frequently, but the current results are comparable with previous reports. Overall, a considerable number of stroke survivors continued to suffer emotional consequences more than one year after discharge. When interpreting these results, it should be

kept in mind that approximately 15% of a normal elderly population are clinically depressed [41].

Living environment

Access: fifty-six subjects answered the questions concerning access to parts of their living environment. **Table 3.** Comparison of results obtained in the current and previous studies for activities of daily living (ADL) skills and satisfaction with stroke services (only studies reporting on outcome 1–3 years after stroke for a hospital-based population are included, except for satisfaction with stroke services)

	Cu	rrent study	Previous studies	
Aspect investigated	No. assessed	Results	Results	References
ADL skills:	56			
mean		16.8 (SD:3.8)	84.7-16.9	5*
median		18	16.5	39
Satisfaction with				
hospital stroke				
services:	44			
mean		18.0 (SD: 4.6)	15.6	18
Satisfaction with				
community stroke				
services:	30			
mean		10.6 (SD: 2.1)	8.8	18

* study in which subarachnoid haemorrhage patients were excluded

SD = standard deviation

Outdoor access caused the greatest problems: 17 (30.4%) subjects reported difficulties with getting in and out of the house (although all patients could actually get out); 11 (20.8%) of the 53 subjects who answered the question about access to their garden had difficulty getting to it, and four (7.5%) were unable to do so.

Indoors, three (5.4%) subjects were unable to get to the bathroom and two (3.6%) could not get to their bedroom; seven (12.5%) could reach their bathroom and bedroom with difficulty; 11 (19.6\%) had difficulty getting to the toilet, and 13 (23.2\%) were still using a commode.

Finances: fifty-two people answered the question about change in financial circumstances after stroke. Thirty (57.7%) reported no change, five (9.6%) reported an improvement, and 17 (32.7%) a deterioration.

Activities

Fifty-five respondents completed the post-stroke FAI and all 57 completed the pre-stroke FAI (post-stroke scores: 3–42, mean: 19.2, standard deviation (SD): 10.6). The post-stroke FAI scores recalculated as percentages of the pre-stroke scores are shown in Fig 1 for 54 subjects. The change in activity scores varied widely: 34 regained more than 50% of pre-stroke activity, and 20 less than 50%—some scoring only 10% of their pre-stroke level—(average percentage score: 59.9, SD: 27.6). Only four regained their pre-stroke level of activity (taken as 100%). Pre- and post-stroke scores were further investigated for the different areas of activity [16]. Outdoor activities were most affected, with a mean reduction of almost 45%. Participation in

domestic chores was reduced by almost 32%. Least affected were leisure/work activities, with subjects scoring 83.6% of their pre-stroke level. However, few patients (13) were working prior to their stroke, and only three (23%) of these had returned to work at the time of the interview.

Correlations (Pearson's *r* statistic) were carried out to determine which aspects of the patients' post-stroke functioning and living environment were related to change in social activities (ie post-stroke FAI scores recalculated as percentages of pre-stroke scores) (Table 4). To assess a possible relation between change in activities and age, correlations between age, the total FAI change scores, and the change scores for each subscale were calculated. Age was significantly inversely correlated with change in outdoor activities (r = -0.38, p < 0.01), but not with domestic (r = -0.22)or leisure/work activities (r = -0.20).

Satisfaction with stroke services

Inpatient services: forty-four patients completed all Hospsat questions. The mean total score was 18.0 (SD: 4.6). A score of 16 is equivalent to agreeing to each question (ie being satisfied). Twenty (45.5%) of these respondents were dissatisfied with at least one aspect of the hospital services. The amount of recovery achieved was most frequently reported as unsatisfactory (30%)—but at one year post-stroke this would not have been dependent on hospital services alone. Information received about the causes and nature of their illness (25.5%), and the amount of therapy received (23.1%) were also commonly reported areas of dissatisfaction. Only 3.7% of respondents disagreed with the statement 'The doctors have



Fig 1. Post-stroke Frenchay Activities Index scores recalculated as percentage of pre stroke scores (n = 54). Thirty-four regained over 50% of their pre-stroke level of activity, 20 regained less than 50% of their prestroke level of activity

done everything to make me well again', and most agreed with the two statements 'I have been treated with kindness and respect by the staff at the hospital' (94.5%), and 'I am satisfied with the type of treatment the therapists have given me' (94.3%).

Community services: only 30 subjects completed all questions on the Homesat. The mean total score was 10.6

 Table 4. Correlations between change in total Frenchay

 Activities Index (FAI) score and other variables

Variable	Change in FAI score (r)		
FAT	0.43*		
Walking, independently	0.54*		
Barthel Index	0.77*		
Attention: no. of errors completion time	-0.20 -0.43*		
Recall of story: immediate delayed	0.18 0.28		
Figure copying	0.27		
HAST HAD: depression anxiety	-0.51* -0.18		
Access to: bathroom bedroom toilet outside	0.051* 0.48* 0.38* 0.64*		
Living with partner	0.20		

FAST = Frenchay Aphasia Screening Test

FAT = Frenchay Arm Test

HAD = Hospital Anxiety and Depression scale

(SD: 2.1). A score of 10 is equivalent to agreeing to each question. Thirteen (43.3%) of the these 30 respondents were dissatisfied with at least one aspect of the community stroke services. The information given about allowances or services was most frequently (19.6%) identified as an area of dissatisfaction. About 15% of respondents were not satisfied with the preparation for return home, and with the services received from the community and hospital outpatient services. All subjects who had used the ambulance service thought it was reliable.

Discussion

Methodological issues

Three methodological issues need to be addressed before discussing the results in detail:

- 1. The population upon which this study was based. The trials included in the statistical overview referred to earlier [1] usually selected patients before randomisation, and the evidence of benefit was strongest for patients with stroke of intermediate severity—that is, not for patients with non-disabling stroke or those with little hope of survival [42], LTRU also concentrated on the intermediate group. Patients included in the present study are therefore likely to be representative of those discharged from any similar unit within a general hospital operating a similar admissions policy.
- 2. *The FAI*. The change in level of activities was determined by calculating the post-stroke FAI score as a percentage of the pre-stroke score. The latter was assessed more than one year after discharge from hospital, so some concern about its reliability is justified. However, despite the long gap between assessment and the pre-stroke period, there are

two reasons why the pre-stroke FAI scores may be reasonably reliable:

- the FAI specifically asks about the frequency of activities, which probably enhances the accuracy of the responses;
- because stroke often changes the activity pattern dramatically, it is our experience that patients are able to remember their pre-stroke frequency of activities. However, a possible danger could be that patients may have too 'rosy' a picture of their pre-stroke activities *because* of the dramatic change in their lives.
- 3. To compare results with previous studies, an attempt was made to identify only those similar to the current study. This was achieved by selecting studies which used a hospital-based sample and reported outcome at 1–3 years poststroke. However, considerable variation was identified, especially concerning sample characteristics and assessment tools.

The age of patients was a particular area of concern—patients admitted to LTRU being significantly younger than those not admitted (see accompanying paper). Younger subjects usually have a better outcome [43–45]. Therefore, possible differences in outcome scores may be due to differences in age, rather than consequent upon the rehabilitation setting.

An additional discrepancy concerning the samples investigated involved the SAH patients. Such patients were included in the current study, whereas in other studies they have either not been included or it was not specified whether they were included. SAH survivors generally have a different pattern of recovery from other stroke patients, which may have added further 'noise' to the comparisons.

Long-term outcome

The main purpose of the current study was to obtain an overview of the outcome of stroke patients one year or longer after discharge from a stroke and neurological rehabilitation unit. The results show that longterm deficits are considerable. Apart from the physical impairments which have been reported in previous studies [5], many survivors also experienced long-term psychological consequences and access problems within and around their homes, and had become less active. Previous work from this unit has emphasised the disruption that stroke causes to almost all aspects of life [20].

Psychological consequences

During the course of this study LTRU did not have a clinical (neuro)psychologist on its staff. Formal counselling services to deal with the trauma of stroke and subsequent losses were therefore unavailable to

patients. Furthermore, retraining of cognitive deficits may have been restricted. Although the effectiveness of cognitive retraining has not yet been convincingly proved, preliminary findings indicate that it can reduce some aspects of cognitive deficits [46].

Psychological problems interfere with the rehabilitation process [47]. They have been related to impaired functional recovery [48], discharge to institutional care [28], and failure to resume social activities [17,31,49]. Psychological support is probably required immediately and for many months after the stroke event.

Access and level of activity

Approximately one-third of participants in the current study experienced problems getting in and out of the house, and one-fifth had problems moving around their own home. Access problems can restrict the ability to lead as normal a life as possible. For example, almost a quarter of the participants were still using a commode, presumably due to difficulties with access to the toilet. Furthermore, access both inside and outside the house was significantly correlated with a reduction in social activities.

A detailed assessment of a patient's environment needs to be carried out before discharge from hospital, and effective coordination with social services is essential for successful adaptation of a patient's living environment. As the current study only indicated the existence of problems (but not what the problems are), further studies are needed to determine the main obstacles.

The level of activities was one of the areas most affected in the current sample. Although this has been reported previously in several studies [16,17, 24,28,50–53], no study has investigated the level of activities after discharge from a specialist neurological rehabilitation unit. In the current study all but four subjects were less active after the stroke. For some, this reduction was minimal, but others performed only 10% of their pre-stroke activities (as measured with the FAI).

One of the aims of LTRU was to develop ways to enhance therapy. This included the active involvement of patients in their own rehabilitation, and the appointment of a leisure coordinator. An observational study of patients on LTRU [54] indicates that patients become more active while they are inpatients, but lack of leisure activity remains a problem in the long-term.

The causes of the reduced activity after stroke are probably complex and multiple. Although physical and functional impairments have been found to be related [17,32], several other factors probably contribute, as a reduced level of activities has been observed in physically restored patients [28,55]. Depression has been found to be related to reduced activity [7,31,32], as have cognitive [31] and language deficits [43], the living environment [55], a feeling of stigma [55], family stress [55], age [31], sex [17] and, in this study, access in and outside the house. Reduction in psychological and access problems may therefore have beneficial consequences for the longer-term level of activities.

It is interesting to note that evaluation of a volunteer stroke scheme—in which volunteers visited the subjects at home and there were meetings at a weekly club—showed a significant increase in the activity (as measured by the FAI) of dysphasic and dysarthric patients who participated [15]. No such improvement was found in subjects who had not participated. It may be that an extension of this scheme to all stroke patients who are interested may help to alleviate the inactivity observed in the current study.

Satisfaction with services

A key aspect of evaluation of new services should be the patients' satisfaction with them. The current study suggests that, in general, patients were fairly satisfied with the available services. The scores concerning inand outpatient services were higher than those previously reported in a general hospital sample [18]. That study and the present one, however, showed a similar pattern of scores on the individual questionnaire items. The aspects of inpatient service with the highest number of dissatisfied patients were:

- the amount of recovery made
- the amount of therapy received while in hospital
- the information provided.

Information received was also the item on the outpatient questionnaire most frequently reported as unsatisfactory. This is disappointing because the LTRU specifically focused on providing patients and family members with information about the rehabilitation programme and the underlying causes and nature of their stroke. Further research should examine which aspect(s) of information provision the patients found inadequate. Simple information booklets, including an introduction to stroke, recovery and rehabilitation, have previously been shown to increase aspects of a patient's knowledge after stroke [56].

Conclusions

This study provides an indication of the wide ranging long-term consequences of stroke after discharge from a neurological rehabilitation ward. Areas which require specific attention include:

- information provision about stroke and rehabilitation
- the psychological consequences of stroke
- access within patients' living environment
- post-discharge activities.

Rehabilitation after stroke should aim not only to remedy the immediate deficits but also to minimise the long-term impact on people's lives.

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