

USE OF HEALTHCARE, IMPACT ON FAMILY CAREGIVERS AND PATIENT SATISFACTION OF REHABILITATION AT HOME AFTER STROKE IN SOUTHWEST STOCKHOLM

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We previously conducted a randomized controlled trial in which early supported discharge from the Department of Neurology at Huddinge Hospital in southwest Stockholm with continuity of rehabilitation at home ($n = 41$) was compared to routine rehabilitation services ($n = 40$) for moderately disabled selected stroke patients. No statistical significant differences were found in patient outcome at 3 or 6 months, but a moderately positive effect in the home rehabilitation group was suggested. In the present study we evaluated resource utilization of health and social care, impact on family caregivers during 6 months after acute stroke and patient satisfaction. A 50% reduction in total hospitalization (initial and recurrent) was observed, from 30 days in the routine rehabilitation group to 15 days in the home rehabilitation group ($p < 0.001$). After discharge, the mean number of home visits in the home rehabilitation group was 12. In total, the routine rehabilitation group had a higher frequency of therapy contacts and daycare in outpatient care. Seventy-eight percent received help from a family caregiver in activities of daily living, yet only 15% had formal home help service. No major differences were found in use of home help service or impact on family caregivers in the form of time devoted to helping the patient or subjective well-being of spouses as per Sickness Impact Profile. Patient satisfaction was in favour of the home rehabilitation group, but a significant difference was only found in active participation in rehabilitation programme planning. In conclusion, early supported discharge with continuity of rehabilitation at home, using goal-directed functional activities based on the patient's personal interests, should be the rehabilitation service of choice for moderately disabled stroke patients fulfilling certain criteria, provided that further evaluation during the first year after stroke reveals no great changes in outcome or resource use. More research into the effectiveness and cost implications of early supported discharge with continuity of rehabilitation at home is needed in other parts of Sweden and in other countries before it can be asserted that the conclusions drawn from this study are applicable elsewhere.

Key words: clinical trial, stroke rehabilitation, stroke management.

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The personal and financial cost of stroke to families, health and social services is substantial. In Sweden, the cost of hospital and outpatient care and social service accounts for 76% of overall Swedish stroke costs (1). On the basis of this information, the number of stroke-related bed-days has been calculated at 3.8 million a year (1). In southwest Stockholm, stroke care accounts for 6% of the total cost of hospital care for inhabitants of the catchment area (2). The needs of stroke patients are often complex, and many professionals are involved in their care both in hospital and the community. Efficient and effective organization, co-operation and communication between the hospital and community teams are prerequisites for successful rehabilitation. While there is a rapidly growing body of data from randomized controlled trials on the effect of various aspects of stroke prevention and management, as yet few cost analyses have been run with regard to gains in stroke rehabilitation (1).

The optimum combination of inpatient, outpatient and/or home rehabilitation is not known. A stroke service based on short-term admission to a stroke unit, followed (where appropriate) by early supported discharge with continuity of rehabilitation in the community seems to have several advantages, as shown in pilot studies (3, 4). In recent randomized controlled studies in Newcastle-upon-Tyne (5, 6) and London (7) a similar scheme was found to be feasible, yielding a saving in bed-days.

We have conducted a randomized controlled trial focusing on moderately disabled stroke patients, in whom early supported discharge from the stroke unit at the Department of Neurology at Huddinge Hospital in southwest Stockholm with a continuation of rehabilitation at home during 3–4 months was compared with routine rehabilitation in hospital, daycare and/or outpatient care. Methodological aspects regarding patient selection criteria, recruitment, randomization and follow-up procedure, and patient characteristics and the impact of the programme on

patient outcome at 3 months (8) and 6 months (9) have been fully reported. The studies (8, 9) suggested a modest difference in favour of rehabilitation at home, with better recovery for social activities, ADL, motor capacity, manual dexterity and walking. The purpose of the present paper is to pinpoint results concerning resource utilization of health and social care, and impact on family caregivers during the first 6 months after an acute stroke and to assess patient satisfaction.

MATERIALS AND METHODS

The patients were eligible for the trial if they had been referred to the stroke unit at the Department of Neurology covering acute care and diagnosed with acute stroke, were continent and independent in feeding, had mental functions within normal limits (MMSE > 23 or for the aphasic patients clinical evaluation by the speech therapist), and showed residual impairment in motor function and/or dysphasia 5–7 days after stroke (8). Eighty-six patients fulfilled the inclusion criteria and 83 gave informed consent. Eighty-one patients, 41 in the home rehabilitation group (HRG) and 40 in the routine rehabilitation group (RRG), were followed up 3 months after stroke and 78, 40 in the HRG and 38 in the RRG, were followed up at 6 months. One patient in the HRG and three patients in the RRG died. One patient in the HRG withdrew for personal reasons one day after discharge and was lost to follow-up. The average age for all patients was 72 years; 54% were men and almost 1/3 lived alone. The HRG showed 10% lower coping capacity ($p = 0.040$), higher frequency of associated diseases ($p = 0.035$), and higher frequencies of abnormal CT scan results on admission ($p = 0.053$) and left hemisphere lesions ($p = 0.057$) (8).

The rehabilitation program (3, 4, 8), which was tailor-made for each HRG patient, emphasized a task- and context-oriented approach using goal-directed activities based on the patient's personal interests. The rehabilitation service was delivered by a team of occupational, physical and speech and language therapists coordinated by weekly meetings. One of the therapists was assigned as care manager for the patient, and she constituted the link between the hospital and the outpatient care. The rehabilitation continued in the patient's home environment for 3–4 months. If additional rehabilitation was required the patients were referred to routine outpatient rehabilitation. Patients in the RRG received their rehabilitation in the stroke unit until discharge or, if required and after evaluation by specialists, in the Departments of Geriatric Medicine or Rehabilitation as inpatients and/or in daycare.

The patients and the spouses were interviewed and evaluated at home by an external assessor, a research physical therapist (LvK), 3 and 6 months post-stroke. The spouse's subjective health-related quality of life was measured by means of the Sickness Impact Profile (SIP) (10, 11). Hours/week spent by spouses in helping the patients with personal and instrumental ADL according to the Katz index (12) after discharge and at

the time for follow-up, or regular help from others were recorded based on information obtained by interviewing the patient and the spouse.

Patient satisfaction in the HRG and RRG was recorded using a questionnaire which has been used in a Swedish study of patients with rheumatoid arthritis (13). The questionnaire was tried out in a pilot study (4) and the questions were modified so as to be suitable for both the HRG and RRG. The questionnaire contained 18 statements with which the patient had to agree or disagree on a five-graded scale. The statements covered seven dimensions as per the taxonomy originally developed by Ware (14, 15), namely, art of care, technical quality of care, accessibility/convenience, finance, availability, continuity, and efficacy/outcome of care. Two further statements were added, covering patients' active participation in discharge and rehabilitation programme planning. The questionnaire was presented to the patient at the follow-up visit 3 months after stroke, and was to be completed after the home visit and returned to the Department of Neurology by mail.

Information of hospital in- and outpatient care, primary care, daycare and visits to private caregivers and mortality was collected from the computerized register at Stockholm County Council; other health-related services were collected by interviewing both patient and caregivers. The number of direct therapy contacts during initial hospitalization was taken from the records of therapists.

Statistical analysis for intergroup differences in resource utilization, health-related quality of life for spouses and patient satisfaction was assessed using the Mann-Whitney U-test and χ^2 . A p -value of 0.05 or less was considered to be of statistical significance.

RESULTS

Hospitalization during the first 6 months post-stroke for HRG and RRG patients is given in Table I. The mean total time for initial hospitalization was 14 days in the HRG and 30 days in the RRG ($p < 0.001$), which implies a considerable reduction (53%) in duration of hospital stay. While mean initial hospitalization time at the Department of Neurology was similar in both groups, almost 50% of the patients in the RRG, but none in the HRG, were referred to geriatric and rehabilitation departments for inpatient rehabilitation. No differences in recurrent hospitalization were found between the groups.

The mean numbers of individual and/or group therapy contacts per patient, including home visits by physio-, occupational and speech therapists, social workers and psychologists in the HRG and RRG during initial hospitalization are given in Table II. The HRG averaged 15 and the RRG 12 therapy contacts/patient at the Department of Neurology. Patients who

Table I. Hospitalization for patients in the home rehabilitation group and the routine rehabilitation group during the first 6 months

	HRG				RRG				<i>P</i> -value
	<i>n</i>	Mean	(Range)	Sum	<i>n</i>	Mean	(Range)	Sum	
Initial hospitalization, total*	41	14	(5–33)	565	40	30	(5–136)	1185	<0.001
Neurology department*	41	13	(5–33)	545	40	14	(5–45)	571	0.440
Rehabilitation department*	0	0			7	43	(11–113)	298	
Geriatric department*	0	0			12	25	(14–56)	304	
Other departments*	3	7	(3–13)	20	3	4	(1–8)	12	0.992
Recurrent hospitalization†	8	7	(2–14)	58	11	6	(2–11)	66	0.392
Total hospitalization†	40	15	(5–42)	616	38	30	(9–136)	1157	<0.001

* HRG $n = 41$, RRG $n = 40$.

† HRG $n = 40$, RRG $n = 38$.

Table II. Therapy contacts during initial hospitalization in the home rehabilitation group (HRG) and the routine rehabilitation group (RRG)

	HRG (n = 41)			RRG (n = 40)		
	n	Contacts		n	Contacts	
		Mean	(Range)		Mean	(Range)
Neurology department						
Physiotherapist	33	10	(2–29)	34	7	(1–13)
Occupational therapist	36	7	(1–31)	32	6	(1–27)
Speech therapist	18	2	(1–6)	13	2	(1–4)
Rehabilitation/Geriatric departments						
Physiotherapist	0	0		18	38	(2–121)
Occupational therapist	0	0		14	30	(1–101)
Speech therapist	0	0		4	6	(1–12)
Social worker	0	0		10	1	(1–3)
Psychologist	0	0		1		3

were referred to geriatric or rehabilitation departments had an average of 60 therapy contacts/patient during their stay in those departments.

Resource use of outpatient care and rehabilitation for patients in the HRG and the RRG during the first 6 months are presented in Table III. There were differences in service utilization between the HRG and the RRG. The HRG had more home

visits ($p < 0.001$) and outpatient visits to neurologists ($p = 0.029$) and the RRG had a higher frequency of daycare ($p < 0.001$), visits to private physical therapists ($p = 0.021$) and hospital outpatient occupational therapy ($p = 0.019$). After discharge, HRG patients received an average of 12 home visits per patient by therapists and more than half of the patients in the RRG used daycare or were treated by therapists associated with

Table III. Outpatient care and rehabilitation for patients in the home rehabilitation group (HRG) and the routine rehabilitation group (RRG) during the first 6 months

	HRG (n = 40)				RRG (n = 38)			
	n	Visits			n	Visits		
		Mean*	(Range)	Sum		Mean*	(Range)	Sum
Hospital outpatient care								
Physician								
Neurology department	35	1	(1–4)	52	23	1	(1–3)	34
Other departments	28	2	(1–7)	60	23	3	(1–17)	72
Nurse and others	5	4	(1–8)	18	6	2	(1–3)	9
Physiotherapist	2	5	(2–8)	10	6	7	(1–15)	39
Occupational therapist	0	0		5	7		(1–21)	35
Speech therapist	6	3	(1–9)	19	3	1	(1–1)	3
Home rehabilitation								
Neurology department	40	12	(2–34)	493	0	0		
Geriatric department	0	0			2	14	(12–15)	27
Day rehabilitation								
Hospital-based	0	0			10	17	(3–32)	172
Community-based	0	0			5	24	(12–36)	120
Primary care								
Physician	25	4	(1–14)	89	20	4	(1–12)	77
Nurse and others	22	7	(1–34)	143	14	6	(1–25)	87
Physiotherapist	2	2	(1–3)	4	4	7	(2–15)	28
Occupational therapist	0	0			2	3	(2–4)	6
Private caregivers								
Physician	20	2	(1–7)	41	16	3	(1–9)	41
Physiotherapist	5	4	(3–6)	20	13	12	(1–35)	162
Speech therapist	1			3	1			2
Chiropractor	0	0			2	3	(2–3)	5
Chiropodist	14	3	(1–6)	41	10	2	(1–3)	15
Outpatient, total								
Rehabilitation†	40	14	(2–34)	549	30	20	(1–54)	594
Care‡	39	10	(1–40)	403	35	9	(1–27)	320

* Mean calculated for patients receiving the cost item. †Occupational, physical, speech and language therapy, daycare, and home rehabilitation.

‡ Physician and nurse.

Table IV. Resource use of health-related services for patients in the home rehabilitation group (HRG) and the routine rehabilitation group (RRG) during the first 6 months

	HRG (n = 40)				RRG (n = 38)			
	n (%)	Visits			Sum	n (%)	Visits	
Mean*		(Range)		Mean*			(Range)	Sum
Home help service	6 (15)	116	(6–355)	696	6 (16)	204	(2–826)	1226
Transportation service	29 (73)				28 (74)			
Alarm	8 (20)				6 (16)			
Technical aids	34 (85)	7	(1–18)	221	36 (95)	5	(1–10)	162
Installation of supporting handles	18 (45)				10 (26)			
Reconstruction of the home	10 (25)				9 (24)			

* Mean calculated for patients receiving the cost item.

the county council, and 1/4 visited physiotherapists or chiropractors in private practice.

Utilization of other health-related services during the first 6 months after stroke is set out in Table IV. Only 15% of all the patients in the study used home help service. The RRG patients receiving home help service had 43% higher frequency of visits than did the HRG. Compared to the RRG, the HRG had non-significantly more technical aids and supporting handles installed at home. Other structural alterations to the patients' home, use of transportation and alarm service were similarly distributed between the groups.

Informal care for patients in the HRG and the RRG during the first 6 months is presented in Table V. Seventy-eight percent of all patients received help from a family caregiver. A gradual decrease in family caregiver input was observed during the period. After discharge, the HRG on average received more help than the RRG, but at 3 and 6 months the HRG received slightly less help than the RRG from family caregivers, but the differences were not statistically significant. The spouse was the main provider of support, except for five patients in the HRG and two patients in the RRG, who received help from their children, grandchildren or others with whom they had a close relationship.

Mean age of all 56 spouses was 69 years and 68% were women. The vast majority, 84% were born in Sweden and had a

basic education, and 21% worked part- or full-time outside the home. There were no major differences in socio-economic characteristics between the spouses in the HRG and RRG. One spouse in the HRG found it impossible to complete the SIP questionnaire owing to language problems. In general, the overall SIP scores, median (IQR) 1 (0–4) at 3 months and 1 (0–5) at 6 months, reflected very modest dysfunction and there were no significant differences between the spouses in the HRG and RRG.

Patient satisfaction with post-stroke care in the HRG and RRG is presented in Table VI. One HRG patient did not wish to answer the questionnaire because she thought that her stroke was not her main medical problem. Reported patient satisfaction with different dimensions of care was 66–98% for all patients. The highest degree of satisfaction was reported for Art of care and Efficacy/Outcome of care, and most dissatisfaction was reported for Active participation in discharge planning and Out-of-pocket expenses for healthcare services. Patient satisfaction leaned in favour of the HRG for Technical quality of care, Finance, Availability, Continuity, Efficacy/outcome of care and Active participation in planning of both discharge and training programmes. For Art of care and Accessibility, however, it was the patients in the RRG who were more satisfied. The only statistically significant difference was for Active participation in treatment programme planning ($p = 0.021$), and this was in

Table V. Informal care for patients in the home rehabilitation group (HRG) and the routine rehabilitation group (RRG) during the first 6 months

	HRG			RRG				
	n (%)	Hours / week		Sum	n (%)	Hours / week		
Median		(Range)	Median			(Range)	Sum	
Family caregivers								
At discharge*	35 (85)	14	(1–35)	506	28 (70)	10	(2–336)	661
At 3 months*	26 (63)	5	(1–28)	186	25 (63)	7	(1–336)	559
At 6 months†	17 (43)	7	(1–18)	127	19 (50)	7	(1–30)	205
Help from other persons†	9 (23)				8 (21)			

* HRG n = 41, RRG n = 40.

† HRG n = 40, RRG n = 38.

Table VI. Patient satisfaction with different dimensions of quality of care, for patients in the home rehabilitation group (HRG) and the routine rehabilitation group (RRG).

Dimension and related matter	Not manifested need in HRG/RRG	HRG n = 40*	RRG n = 40
		Satisfied/Uncertain/ Dissatisfied	Satisfied/Uncertain/ Dissatisfied
Art of care			
Sympathy from staff		37 / 2 / 1	40 / 0 / 0
Kind treatment		39 / 1 / 0	40 / 0 / 0
Technical quality of care			
Good information		36 / 2 / 2	35 / 4 / 1
Training specially tailored to the condition		39 / 1 / 0	38 / 1 / 1
Technical aids	9 / 12	31 / 0 / 0	25 / 1 / 2
Workplace adaptation	37 / 39	3 / 0 / 0	1 / 0 / 0
Home adaptation	19 / 27	20 / 0 / 1	11 / 0 / 2
Public transport	9 / 7	30 / 0 / 1	29 / 1 / 3
Accessibility/convenience			
Easy to get in touch with staff		35 / 5 / 0	36 / 4 / 0
Finance			
Cost of care		27 / 6 / 7	21 / 7 / 12
Availability			
Contact with all expertise needed		38 / 2 / 0	35 / 3 / 2
Adequate (enough) training		36 / 2 / 2	30 / 3 / 7
Continuity			
Meeting same staff during training		38 / 1 / 1	37 / 1 / 2
Efficacy/outcomes of care			
Satisfied with the care received		40 / 0 / 0	39 / 0 / 1
Participation in discharge planning		28 / 2 / 10	25 / 3 / 12
Participation in planning training programme		32 / 2 / 6	21 / 9 / 10

* One patient did not complete the questionnaire.

favour of the HRG. In the RRG, causes for dissatisfaction were reported for: continuity of physicians, by two patients; lack of assistance rail, by one patient; lack of bathtub seat and supporting handle in the bathroom, by another patient; and shortage of speech therapy, by one patient. In the HRG, cause for dissatisfaction was reported for continuity of nursing in primary care by one patient.

DISCUSSION

The major goal of a health-economic evaluation of any given stroke rehabilitation service is to ascertain that optimum value is being obtained as regards resource allocation, not merely to reduce healthcare costs. In order better to enable analysis based on objective evidence of outcome, an appraisal of resource use of an alternative rehabilitation approach should preferably be performed in tandem with the randomized controlled trial. This paper focused on resource utilization during the first 6 months after acute stroke, a time period during which one would expect most of the resources for care and rehabilitation of moderately disabled stroke patients to be used.

This study demonstrated that early supported discharge following an acute stroke with a continuation of rehabilitation at home by a team associated with the Department of Neurology, implied a considerable reduction in total (initial and recurrent) hospitalization, lower frequency of contacts/visits in outpatient rehabilitation and higher in outpatient care to physicians, nurses and chiropodists. One explanation for the increase in resource

use of outpatient care for the patients in the HRG might be the higher frequency of comorbidity, diabetes in particular (8).

The degree of service organization may be an important factor in determining stroke service effectiveness. Community rehabilitation provided by a variety of municipality based rehabilitation services, not specialized in stroke and not consistently coordinated through multidisciplinary team meetings, has not shown to be effective in comparison with rehabilitation on a stroke ward (16). Important factors contributing to service effectiveness in our study might be that the stroke service had a close link to the stroke unit, and the outreach rehabilitation team was coordinated by a case manager, which implied both stroke competence and continuity.

Most of the trials included in a review of services for reducing duration of hospital stay for acute stroke patients have recruited only a minority (13–45%) of stroke patients admitted to urban hospitals (17). Hence the results of these trials may only be relevant to a proportion of all stroke patients, particularly those who live within a relatively local area and have residual disability which is not too severe.

The resource utilization of health-related services and impact on family caregivers incurred by the HRG were lower and patient satisfaction higher than those of the RRG. Findings of the two trials in Great Britain (5–7) also showed an advantage of an alternative management of stroke services similar to this study. It has to be said, however, that these results might not be generalizable to other settings and that our results may not be directly comparable with such studies.

One could always argue that the average burden of care per patient in hospital would increase and call for increased staffing if the less care-demanding patients were to receive rehabilitation in their own home to a greater extent. However, any expected savings would imply the bringing about of a total re-allocation towards less resource-demanding forms of rehabilitation (18). The extensive use of different organizational forms of outpatient rehabilitation in routine stroke care found in this study agrees with the findings of a study in Stockholm County, which likewise highlighted the lack of responsibility for overall planning and organization geared to a coherent and continuous caring chain for stroke patients (19).

Despite the differences in therapy and daycare contacts and/or visits per patient by the HRG and RRG, total time spent in meaningful and goal-directed therapeutic activities may not necessarily have been different. Our pilot study showed that patients spent over an hour a day in self-directed training between therapy sessions at home (3). In contrast, several studies have reported that most stroke patients in routine rehabilitation spend much of their time inactive in hospital (20) and that there is very little evidence of self-directed exercises (21,22). The result of the evaluation of patient satisfaction might indicate that HRG patients play a more active part in planning the rehabilitation programme than do RRG patients, and it is thus likely that the relevance of activities to patients in the HRG was higher.

The slightly higher resource utilization of technical aids and bathroom supporting handles in the HRG might prove cost-efficient in the long run if it contributes to enable the patient to be independent in personal ADL for a longer period of time. The number of patients using health-related transportation services was equally distributed among the HRG and RRG.

A remarkable feature was the extensive contribution of help by family caregivers in comparison with that furnished by formal home help service. There was no indication that the early discharge scheme together with the home rehabilitation programme increased the need for formal home help service, or generated greater stress on spouses as seen from health-related quality of life or time devoted to helping the patient, despite the HRG patients' lower coping capacity and more severe comorbidities (8). The methods used to evaluate impact on family caregivers used in this study do not fully appreciate the burden of care experienced by the caregivers of stroke patients.

To date, patient satisfaction has only been reported in one randomized controlled study designed to evaluate an early discharge scheme for patients with stroke (23). The fact that many patients both in the HRG and the RRG in our study, despite the not strictly anonymous procedure, expressed dissatisfaction, and that only one patient refused to answer the questionnaire, render it possible to use the procedure as described above. Despite reported limitations in measuring patient satisfaction (24), overall HRG patients were more satisfied with care, and especially with active participation in the planning of their rehabilitation programme. Patient perceptions of what constitutes good quality of care can also

incorporate the dimension of the socio-cultural atmosphere, i.e., if the rehabilitation setting is a home-like environment where the patient's wishes and needs take priority over fixed routines (25), a dimension only partially addressed in this study by enquiring about patients' active participation, as reported above. Despite the fact that only 16% of all patients at entry to the study perceived their economic situation as insufficient (8), 33% in the HRG and 48% in the RRG perceived out-of-pocket expenses of care as constituting a great burden to them. It is not known whether a patient's economic situation affects compliance with treatment regimes or subjective well-being.

We therefore conclude that early supported discharge with continuity of rehabilitation at home should be the treatment of choice for moderately disabled stroke patients fulfilling certain criteria, provided that further evaluation during the first year after stroke reveals no great changes in outcome or resource use. More research into the effectiveness and cost implications of early supported discharge with continuity of rehabilitation at home is needed in other parts of Sweden and in other countries before it can be asserted that the conclusions drawn from this study are applicable elsewhere. We expect that such information will allow rehabilitation resources for stroke patients to be organized in the most rational and cost-effective manner.

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