# INTERVENTION DESIGN FOR REHABILITATION AT HOME AFTER STROKE A PILOT FEASIBILITY STUDY

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ABSTRACT. This study aimed at identifying the characteristics and feasibility of rehabilitation at home for acute stroke patients in south-west Stockholm. A population-based systematic sample of 16 patients, fulfilling defined criteria, was selected from approximately 1/3 of the stroke patients having been in hospital for one week or more at a neurology department, and offered early discharge in combination with home-based rehabilitation as an alternative to sustained rehabilitation in hospital. Fifteen patients, mean age 68.2 years, male/female ratio 9/6, independent in feeding and continent one week after acute stroke, participated in the study. The most important components of the home-based rehabilitation programme were that: 1) one therapist was selected as case-manager using the other therapists on a consultant basis; 2) the training sessions consisted of different task-specific activities, based on the patients' personal interest; 3) education and individual counselling were offered to all spouses; and 4) adherence to structured training between therapy sessions was promoted. The length of such programmes varied from 4 to 19 weeks after discharge and the mean number of home visits was 11. Reported time for training between therapy sessions for 14 patients was mean 1.2 hours per day. The patients' lifestyle activities, personal and instrumental ADL, and motor capacity at 3, 6 and 12 months after stroke, assessed by validated and reliable methods, followed patterns similar to those reported for other stroke patients. The mean time in hospital for patients in the study was 14 days; for patients with similar ADL capacity but not included in the study it was 27 days. Rehabilitation at home, in some cases combined with early discharge, may be suitable for a large proportion of incident acute stroke patients, as well as cost-effective.

Key words: activities of daily living, cerebrovascular disorders, disability, home, rehabilitation.

Clinical and research attention in stroke care has been focused on managing the acute stage of stroke recovery and evaluating the effectiveness of early hospitalbased rehabilitation programmes (17, 31). While valuable conclusions about the effectiveness of some interventions in this field have been obtained from reviews of studies on rehabilitation (27, 30), the authors agreed on the need for further research. In contrast to studies focusing on the evaluation of specific techniques requiring small, well-defined, selected groups of patients (30), a major research avenue is proposed comprising so-called policy studies where the development of hospital-home, function-based stroke rehabilitation programmes and cost-benefit appraisal are included (28, 29, 37). In such activities the boundaries between research and development work might not be well defined (4). Large scale assessment of alternative delivery systems is an important part of the effort to control costs and improve access to health service (18). Before major changes in the system can be designed and implemented, pilot studies where individual patients are studied in depth are often needed to assess which type of changes are feasible and offer the greatest promise (26).

The purpose of this study was to lay the foundation for a large formal experiment, currently ongoing, given the above-mentioned theoretical basis for development for stroke rehabilitation programmes and the results of prior studies (3, 29, 37). Based on a set of exploratory, pilot cases, the objectives of the present study were to identify characteristics of the target incident patients

and to describe the content and feasibility the rehabilitation programmes implemented.

# MATERIALS AND METHODS

Patient selection

From September 15th onwards, in south-west Stockholm (SWS)—an area with a population of 343,550 inhabitantshospital care for residents with suspected acute stroke was provided by the Neurology Department at Huddinge Hospital (HH). The In-patient Diagnosis Register of Stockholm County was used both to identify all patients with TIA and acute stroke diagnoses, ICD-9 code 430-37, admitted to the HH Neurology Department as well as to calculate duration of hospital stay after acute stroke.

Between September 15th 1991 and May 31st 1992, 658 patients were admitted with acute stroke diagnoses on 910 different occasions. On 403 occasions, the patients were discharged within five days of admittance to hospital. Based on the remaining 507 occasions, 173 patients were evaluated according to Katz' ADL index (19), five to twelve days after hospitalization. For 10 patients evaluation was delayed, taking place after 12 days. Grade A indicate complete independence in personal ADL, and grade G complete dependence.

A subsample of the 173 patients of a size limited by availability of therapists, was offered rehabilitation at home as an alternative to sustained rehabilitation at HH Neurology Department, or transfer to different rehabilitation or geriatric departments for continued rehabilitation there. Evaluations of needs for further rehabilitation were routinely made by consultants from the rehabilitation and/or geriatric departments. Criteria for inclusion in the intervention sample were: 1) age <80 years at day of admittance; 2) independence in toileting according to Katz' index of ADL; 3) clinical signs of dysphasia or dysarthria and/or impaired motor capacity (23, 24), and 4) Mini Mental State Exam (MMSE) score (11) >23. A visual scanning test (12) was performed on both right- and left-sided stroke patients. subacutely.

### Design of intervention and assessment

A home rehabilitation programme, individually planned by staff physical, occupational and speech therapists associated with the HH Neurology Department, was drawn up for each patient who passed the entry criteria and was willing to participate. After discharge, one of the therapists was selected to be case-manager, using the other therapists on a consultant basis. The case-manager was responsible for: 1) most of the therapy at home; 2) coordination between HH therapists; and, 3) contacts with the relatives and home service assistants. The therapists who were assigned to treat the patient at home, conducted the first assessment and initial treatment, and planned the first home visit while the patient was in hospital. The patients were offered regular therapy at home from the first day until three to four months after discharge. If sustained therapy was needed, transfer to therapists in primary health care was to be organized.

The programme was tailor-made for each individual taking into account neurological deficits, restriction in ADL-capacity due to co-morbidity, and patients' personal interest in certain activities. Specific and measureable goals, accepted by the patient, were set (7). Feedback was provided to the patient on how he/she was performing as regards these

goals. "Learned non-use" (32), compensation with the intact extremity in functional situations, was prevented. Education and individual counselling (10) were systematically offered to spouses and home service assistants. The model of neurological rehabilitation used in this study was based on the task-oriented approach (6) which assumes that control of movement is organized around goal-directed, functional behaviour rather than on muscles and movement patterns. The patient and the family were encouraged to be active participants in the rehabilitation programme and adherence to structured training between therapy sessions was promoted (1). The patients were asked to keep diaries on time for and type of training between therapy sessions.

Follow-up visits were scheduled three, six and twelve months after stroke. Interviews and assessment were conducted by two of the authors (LWH and MH) using the following procedures:

1) Since it has been suggested that certain personality traits will affect desirable health behaviour such as adherence to therapeutic regimes (22) and that self-motivation is highly correlated with attraction to physical activity and perception of exercise as having value for health (8), a Swedish version of the Sense of Coherence (SOC) Questionnaire (2) was used to measure the patients' SOC scores. The mean SOC score was compared with normative data from a Stockholm county population sample, mean 151 (SD 18, range 105-186) (22). Patients' adherence to structured training between therapy sessions was examined, taking into account individual SOC scores.

2) Lifestyle activities, i.e. other than personal care, undertaken by the patients before and after stroke, during the preceding three to six months, were measured using the Frenchay Activities Index (FAI) (34).

3) Information about dependence on another person in performing personal and instrumental ADL was recorded using Katz' ADL index extended with cooking, shopping. cleaning and transportation as per Hulter Asberg & Sonn (15), based on patients' self-reported performance and given the value one for independence and zero for dependence in the different activities.

4) Motor capacity on the paretic side was assessed using the chart developed by Lindmark & Hamrin (23, 24).

5) Walking speed was tested by asking patients to walk 10 m inside their homes or, if possible, 20 m on the level outside their homes, using any aid they wished and as fast as they could with safety. Their time (in seconds) was recorded. Normative data (35) were used to classify patients' walking speed over 10 m as normal or slow for their age.

6) Self-reported verbal behaviour in speech situations was measured using the verbal Performance Rating Scale (VPRS) (36) for those patients with dysphasia and dysarthria. Subjective dysfunction in communication was obtained from the

Sickness Impact Profile (SIP) scores (5).

The project was approved by the ethics committee at Huddinge Hospital. Immediate admittance to hospital was offered in case of need or change of interest. Statistical significance of changes over time were calculated using the Wilcoxon signed rank test for lifestyle activities, ADL and motor capacity.

# RESULTS

Admitted patients

During the period February 1991-April 1992, 16 stroke patients were offered early discharge and

Table I. Characteristics of patients (n = 15) in the pilot study

Gender (female/male)	6/9
Age (mean)	68.2
(range)	45-79
Final diagnosis	
Cerebral infarction	14
Cerebral hæmorrhage	1
Side of predominant neurological deficit	
Right/Left	7/8
Functional state, on admission	
Fully conscious/not fully conscious	13/2
Motor deficit, arm	15
Motor deficit, leg	15
Motor deficit, face	6
Sensory deficit, arm	4
Sensory deficit, leg	5
Dysphasia	1
Dysarthria	6
Defective visual scanning	5*
Minimental state exam score	
mean	27.2**
range	24-30
Family situation	
Living with spouse	10
Living alone	5
Professional status	
Retired (owing to age or illness)	10
Employed (one patient reported sick)	5
Planned treatment before selection	
At Neurology department	5
At Rehabilitation units	5***
At Geriatric units	5***
Sense of coherence score	
12 months after stroke	SOON NOWHER
mean	153****
SD, range	23,97-184

<sup>\*</sup>The test was performed on 13 patients.

rehabilitation at home. Fifteen patients, mean age 68.2 (range 45–79), six females and nine males, seven with right hemipareses, including one patient with dysphasia, and eight with left hemipareses accepted it. One male patient rejected the invitation. Different personal, clinical and functional characteristics of the 15 patients are shown in Table I. The SOC scores for our patients and those reported for the Stockholm county population sample (22) did not vary to any appreciable extent.

The diagnoses documented in the patients' medical records before the stroke episode under observation are listed in Table II. Twelve of the patients in our study had impairments in the musculoskeletal and

Table II. Medical history of 15 consecutive patients in the pilot study

Patient number	Diagnosis
1	Manifest stroke, spinal stenosis
1 2 3	Diabetes mellitus, herpes zoster
3	Transient ischæmic attack, angina pectoris, rheumatoid arthritis
4	Hypertension, myocardial infarction (2), angina pectoris, pulmonary oedema, spine orthopædic operations (4), systemic lupus erthematosus
5	Stroke, hypertension, myocardial infarction
	Hypertension, diabetes mellitus, gastric ulcer
6 7 8 9	Prostate disorder
8	Transient ischæmic attack
9	Myocardial infarction, angina pectoris, chronic obstructive lung disease
10	Healthy
11	Hypertension, diabetes mellitus
12	Surgery due to gonarthrosis, gastric ulcer
13	Myocardial infarction (2), angina pectoris, intermittent claudication, bilateral senile cataract
14	Hypertension, silicosis, herpes zoster
15	Stroke, goitre

cardiopulmonary system, which contributed to their disability.

The numbers, age and gender by ADL-grade 5–12 days after admittance in the sample of 173 patients and in the sub-sample of 15 patients who took part in the pilot study are shown in Table III. According to Katz index, 49% of the 173 patients had ADL grade A–E and 51%, ADL-grade F–G. Although the age range within each ADL-grade was wide, the median age was somewhat lower for patients within each ADL grade A. The male/female ratios in ADL grades A–E were approximately 0.5, but there was a higher proportion of women among the more disabled patients. Patients in the pilot study were recruited only from those with ADL grades A–E. Their median age was lower compared with that for all patients with ADL grade A–E and the male/female ratio was 1.5.

### Intervention

Time for discharge from the HH Neurology Department and frequency of contacts with different paramedical professionals during both hospital stay and home-based rehabilitation for each patient are shown in Fig. 1. During hospital stay all patients had frequent contacts with physical and occupational therapists.

Mean number of therapy sessions at home for each patient was 11, range 4-27. Intensity varied from 4

<sup>\*\*</sup> The test was performed on 14 patients.

<sup>\*\*\*</sup> Already accepted and on waiting list for sustained rehabilitation.

<sup>\*\*\*\*</sup> The test was performed on 14 patients, one patient died before six-month follow-up, but had a SOC score of 196 at three-month follow-up.

Table III. Number of patients, their median age, gender and number of deaths within six months by ADL-function 5–12 days after hospitalization in a sample of 173 patients and in the subsample of 15 patients in the pilot study

	All patients				In home treatment			
ADL-grade	n = 173	Median age (range)	Men/Women	Deaths	n = 15	Median age (range)	Men/Women	Deaths
A	55	68 (26-91)	30/25	2	4	68 (62–74)	4/0	0
В	8	72 (52-88)	3/5	0	4	68 (52-78)	0/4	0
C	5	78 (56-93)	2/3	0	2	67 (56-78)	2/0	0
D	2	81 (76-86)	1/1	0	1	76	1/0	0
E	15	78 (45-87)	9/6	2	4	77 (45-78)	2/2	1
F	39	73 (52-90)	14/25	3		1900	**	
G	49	77 (55-93)	17/32	28				

per week after discharge, to 1 per 2–3 weeks by the end of the treatment period, evincing a general pattern of the gradual process of discharge from therapy. The length of the rehabilitation programme varied from 4 to 19 weeks after discharge, depending on the needs of patient and spouse.

Different task-specific activities used for training the patients at home are shown in Table IV. Activities using manual dexterity: cooking and washing up; and walking in- and outdoors were most frequently used. The number of activities used for each patient was median 8, range 6–12. In order to compensate for different dysfunctions, 13 patients also received prescriptions and instructions for technical aids for personal care, transfer and/or domestic activities. Intervention to prevent impairements in the musculo-skeletal and cardiopulmonary system was done in 13 patients. Information, instruction and/or support to relatives and/or home-help assistance were offered to 11 out of 15 patients.

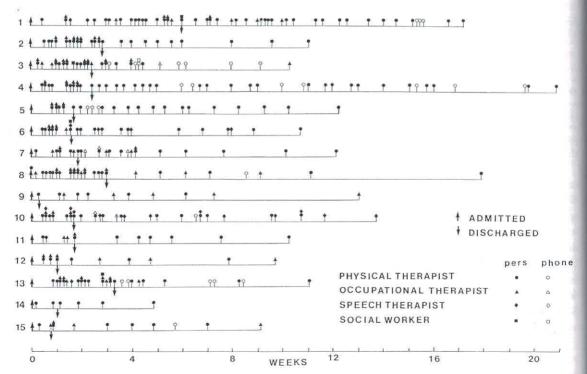


Fig. 1. Time for discharge and frequency of personal (pers) and telephone (phone) contacts with paramedical professionals during hospital stay and rehabilitation at home for consecutive patients in the pilot study.

Table IV. Number of patients (n = 15) using different task-specific activities in training at home

	1372	
Activity	n	
Personal ADL		
Eating	7	
Continence	1 3	
Transfer	3	
Dressing	9	
Bathing	6	
Instrumental ADL		
Cooking	14	
Transport	11	
Shopping	10	
Cleaning	8	
Other specific activities		
Walking indoors	13	
Walking outdoors	12	
Manual dexterity*	15	
Physical activities**	6	
Social activities***	5	
Speech and articulation	2	
Preparatory work training and		
visits to place of work	2	

Examples of activities used:

with local stroke club.

The home environment offered ample opportunities to set functional, achievable and measurable goals which were of primary concern to the patients. Such goals might entail: 1) starting to put the dishes in the cupboard on the lowest shelf after washing-up and then progressing to higher shelves; 2) starting to walk indoors with walking frames and then progressing to walk outdoors without assistance; or 3) starting to knit with large-sized needles and then progressing to normal size. In general, the goals implied improvement or maintenance of function. In some instances, due to co-morbidity, the objectives were to modify the rate of decline, especially for patients with other impairments contributing to their disability. Fourteen patients with SOC scores above 126 reported adherence to structured training between therapy sessions. One patient scoring 97 was not motivated to practise between therapy sessions. According to the diaries from patients and notes from therapists on 14 of 15 patients, mean time spent in training per day, between therapy sessions, was 1.2 hours, range 0.5-2.8.

### Outcome

All patients took part in the three-month follow-up.

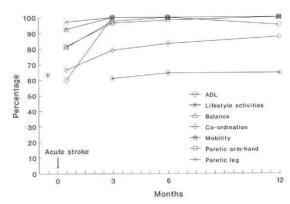


Fig. 2. Median percentage of scores for 14 surviving patients in: a) pre-stroke lifestyle activities and b) personal and instrumental ADL, motor capacity and lifestyle activities at discharge and three, six and twelve months after stroke. Time-point for discharge after stroke plotted at the mean interval-value (14 days).

Only 14 of them were alive and able to participate in the interview and assessment six and twelve months after stroke. One 76 year-old-female patient had hip fracture and a male patient recurrent stroke, 17 weeks and five months after acute stroke.

The median percentage scores for lifestyle activities, ADL and motor capacity at different time points, before and after stroke, are shown in Fig. 2. All patients were already restricted in lifestyle activities before stroke. Such activities were affected three months after stroke, -2.2% (p-value <0.05), but not at later evaluations. There was an improvement in ADL-capacity from 60% at discharge to 100% three months after stroke (p-value <0.05). While eight of the surviving patients regained independence in personal and instrumental ADL, five patients regained independence solely in personal ADL. Six months after stroke nine patients were independent in personal and instrumental ADL. One patient who had recurrent stroke became dependent in both personal and instrumental ADL. Twelve months after stroke, the median ADL capacity had slightly decreased.

Improvement in motor capacity occurred from discharge to three months after stroke (*p*-value <0.05). Minor improvement occurred between three and 12 months. Walking ability for patients at discharge, and three, six and 12 months after stroke is presented in Table V. Three months after stroke 12 patients walked at normal walking speed. Between three and 12 months after stroke, one patient with recurrent stroke and another patient with a medical history of surgery due to gonarthrosis showed

Writing, handicrafts, carpentry and different pastime and leisure activities.

<sup>\*\*</sup> Gardening, excursions, gymnastics, dancing, swimming.
\*\*\* Going to town, cultural event, arranging peer contact

Table V. Number of patients in different categories of walking ability at various time points after stroke

In brackets number of patients who achieved normal speed for their age.

Time	Number of patients					
after stroke	Without aid	With aid	With aid and supervision	Unable to walk		
At discharge	1	13	0	1		
3 months	11(11)	2(2)	2(0)	0		
6 months*	10(10)	2(2)	1(0)	1		
12 months	10(10)	2(1)	1(0)	1		

<sup>\*</sup>One patient died before six-month follow-up.

deterioration from normal to slow speeds for their age. Another patient with spinal stenosis deteriorated from slow speed to being unable to walk by the 12-month follow-up.

According to VPRS, one patient with dysphasia and one with dysarthria reported that they were affected by several people listening to them speaking. The patient with dysarthria also reported that she was thinking of her speech problem during her daily activities.

According to SIP, both patients found it difficult to write or type. The patient with dysarthria also reported loss of speech control under stress.

# Follow-up of samples

Within six months, 92% of the 85 patients with ADLgrade A-E had been discharged to their own home. The corresponding figures for the 88 patients with ADL grades F and G were 56% and 10%, respectively. The median duration of hospital stay by ADLgrade for patients discharged to their own home within six months, for patients not affected by the intervention and for patients in the pilot study, are depicted in Fig. 3. The mean duration of hospital stay for patients in the pilot study was 14 days, SD 10, range 2-42, and for patients with ADL-grade A-E but not affected by the intervention, 27 days, SD 36, range 5-181. One third of the patients with ADLgrade F-G were discharged to their own home after an average hospital stay of 103 days, SD 56, range 10-181. The above-mentioned patient who rejected participation spent 134 days at hospital before being discharged to his own home.

In the sample of 173 patients evaluated by Katz' ADL index, lethality after six months was 6%, 8%

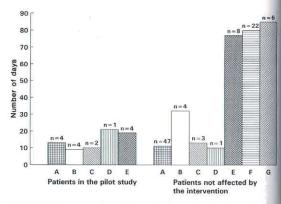


Fig. 3. Median duration of hospital stay by ADL-grade for patients in the pilot study and for patients not affected by the intervention discharged to their own home within six months after an acute stroke episode.

and 57% for patients with ADL-grades A-E, F and G, respectively (see Table III). The patient with hip fracture, among the pilot cases, died at home five months after acute stroke, probably due to a new stroke.

# DISCUSSION

The group of patients in our study was not representative of patients with ADL-grade A-E, since it was created for: 1) the group of patients who need rehabilitation after stroke; 2) those for whom rehabilitation at home was appropriate; and 3) those for whom early discharge was feasible. With regard to distribution of patients in hospital by ADL-grade, our results agree with earlier findings from a Swedish study (16) where approximately 50% of the stroke patients admitted to hospital had ADL-grade A-E according to Katz' index within one week after stroke. Taking into account the above and that: 1) 21% of screened individuals in a Stockholm borough, aged 75 years and over, had MMSE score <24; (13) and 2) 17% of patients discharged after more than 10 days with stroke were affected with certain disorders and not deemed suitable for rehabilitation at home (29), we estimate that 25% of all stroke patients in hospital for more than one week are suitable for rehabilitation at home. Furthermore, since: 1) 1/3 of patients with Katz' ADL-grade F-G, i.e., approximately 50% of the patients still in hospital after one week at SWS, were discharged to their own home after approximately 3 months (see Table III); and 2) frail stroke patients did not benefit more from day hospital care than from training at home (14, 38) we estimate that almost 50% of all stroke patients requiring

rehabilitation are suitable for home programmes after acute stroke.

Rehabilitation after hospital discharge has been considered essential in rehabilitation of stroke patients (21). The appointment of a case-manager at the acute-care hospital ward, which characterizes our organizational model, had several advantages. It constituted a link between hospital and out-patient care and guaranteed continuity both in time and personnel. Discharge from hospital depended more on the patient's agreement and health status than on accessibility to rehabilitation at the Primary Health Care. An important implicit message to patients and spouses was that post-stroke recovery was possible even after discharge from hospital care and that the home environment offers ample opportunities for practice.

In the course of trying out new rehabilitation procedures, models are likely to collide with current conceptions about professional practice (20). The use of a therapist as a case-manager, who coped with wider domains of functioning than is currently in vogue while using the other professionals on a consultant basis, was feasible with our patients and our therapists. Our experience from rehabilitating the patient at home, combined with the provision of education and individual counselling to the spouse, is that patient-spouse interplay became more evident, which in turn made it easier to detect over-protective or unrealistic attitudes.

The results of our study were concordant with studies showing a decrease in lifestyle activities after stroke (34) and that certain personality traits, possibly reflected by SOC scores, affect adherence to therapeutic regimes (8). As in other studies (9, 33) the major part of our patients' recovery in ADL, motor capacity and walking occurred during the first three months after stroke and only minor changes were seen between three and six months. As reported in a study in the U.S.A. (25), the patients with language and speech disorders in our study were suitable for treatment at home also in Stockholm.

In accordance with official guidelines and our results, development of community-based rehabilitation for stroke patients accompanied by a reduction in the cost of hospital care is a realistic goal and, as seen from the difference in resource utilization of hospital care among patients with ADL-grade E, may also prove cost-effective. Detailed results of a health/economic appraisal of this pilot study will be reported.

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