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STROKE REHABILITATION IN STOCKHOLM. BASIS FOR LATE INTERVENTION IN PATIENTS LIVING AT HOME

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ABSTRACT. In order to identify the basis for late-therapy intervention in patients with stroke, we studied a population-based sample of 20 patients. The requests were that they should be living at home 1–3 years after being hospitalized, and that they had declared themselves in need of rehabilitation services. The assessment of abilities and activities of the patients was related to the model of human occupation developed by Kielhofner and co-workers. Most individuals reported a change in activity and interest patterns after stroke, and high motivation in current activities. The cognitive functions were within normal limits for all tested patients. However, the motor abilities and verbal performances were frequently affected and varied considerably. About 3/4 of the patients were not motivated to change their level of dependence in personal and instrumental ADL. Social and leisure activities outside the home were identified as the most promising goals for community-based rehabilitation programmes. Focusing on such activities, potential improvement in quality of life for this population could be achieved by individually-planned rehabilitation programmes using non-professional collaborators and patient organizations.

Key words: activities of daily living, disability, epidemiology, rehabilitation, stroke.

This study is part of a project aimed at developing and evaluating task-oriented, home-based therapy programmes for persons who have had a stroke (12). In a prior study, we investigated the subjective need for rehabilitation, among a potential target population in the South-west Stockholm county (SWS) and explored the possible collaboration of non-professional assistants in such programmes (13). The characteristics of the groups—interested and not interested in further rehabilitation—regarding current use of rehabilitation services and satisfaction with health care were also described. In this study, we made a detailed assessment of the prevalent stroke patients living at home and interested in further rehabilitation.

The aims of the present study were: 1) to evaluate the level of occupational functioning; 2) to compare dependence in activities in daily living (ADL), and activity and interest patterns as between different groups; 3) to identify goals for therapeutic intervention; 4) to describe the non-professional assistants perceived knowledge of stroke and their help with training; and, 5) to provide data used to validate the information obtained by telephone (13).

MATERIAL AND METHODS

This study focused on the above-mentioned population-based sample, consisting of 18 males and 6 females who had had a stroke in the period 1987–1989, who were free from specific selected comorbidity, surviving as of December 1989 and who reported dysfunction due to stroke and subjective need for rehabilitation. These 24 patients received a letter which 1) described the purpose of a proposed home visit, and 2) explained that their participation was voluntary and that a refusal would not in any way affect their future relationship with health-care services. Within a week, the patients were contacted by telephone. By this time, 4 of the 24 patients had, for various reasons, changed their minds regarding interest in further rehabilitation. From August to October 1990, 3 of us (LWH, MH and BS) experienced in stroke care and rehabilitation, conducted interviews and performed the tests on 20 patients, 14 males and 6 females. Those patients who had reported communication problems during the telephone interview were also visited by the speech pathologist (AH).

The assessment of occupational functioning was related to a conceptual model which considers occupational behaviour as those activities in which a person is engaged during most of his waking time: work, play and daily living activities (7). The model conceptualizes how occupational behaviour is moti-

Table I. *Ratings given by each of the two observers for different categories of the Assessment of Occupational Functioning of 19* prevalent stroke patients living at home*

	Observer 1					Observer 2					Average of means
	Mean	SD	Median	W	*p*-value	Mean	SD	Median	W	*p*-value	
Personal causation	1.47	0.51	1	0.640	0.0001	1.68	0.58	2	0.598	0.0001	1.58
Values	1.37	0.50	1	0.616	0.0001	1.47	0.77	1	0.836	0.0032	1.42
Habits	1.53	0.70	1	0.724	0.0001	1.42	0.77	1	0.810	0.0011	1.48
Skills	1.89	0.66	2	0.795	0.0006	2.05	0.71	2	0.727	0.0001	1.97

* One patient was excluded due to severe aphasia.

vated by 1) personal causation (a person's belief and expectations about his or her effectiveness), 2) values (image of what is good, right and/or important) and 3) interests (disposition to find occupations pleasurable). Personal *causation* includes a person's conviction that outcomes in life are related to personal actions and that he or her has important abilities that are useful in his or her life situation and expectancy of success. A shortened version of Watts et al.'s "The Assessment of Occupational Functioning" was used to obtain self-reported functional capacity (5). It consisted of a semi-structured, tape-recorded interview and a series of items to be rated on a 5-point scale, from absent up to fully adaptive, based on the interview, concerning: 1) personal causation; 2) values; 3) habits (images guiding the routine and typical way a person performs); and 4) skills (abilities a person has for the performance of various forms of purposeful behaviour). The level of interest and pleasure in particular activities was identified using a modified version of the "Interest Checklist" (11, 16). This contained 52 items for which the patients indicated both their level of interest before stroke, their current participation, and whether they would like to pursue the activity in the future. Patients were also asked to add other activities of their own choice. "The Occupational Questionnaire" was used to record self-reported time for different activities during an ordinary weekday (14). Using a three-graded scale the patients rated personal causation, values and interests for each activity. The activities were classified as either rest, personal care, daily living tasks, work, physical training, leisure activities at home or leisure activities outside the home.

Information about degree of dependence on another person in performing personal and instrumental ADL was obtained by interviewing the patients or, in case of severe aphasia, the spouse or the home-service assistant. Personal and instrumental ADL (cooking, shopping, public transportation, cleaning), dependence in performing ADL and different grades (0 indicating complete independence and 10 complete dependence) were defined according to Åsberg & Sonn (6).

Walking was assessed by observing the patients walking in their own home. The ability to perform active movement and rapid movement changes was measured in both affected and intact sides using a shortened version of the Lindmark & Hamrin scale (9, 10) containing 15 of 35 items. A routine clinical protocol was used on 6 aphasic patients. A modified Swedish version of the Amsterdam-Nijmegen Everyday Language Test (ANELT) (3) was used for measuring communicative ability for patients with minor aphasia. Self-reported verbal behaviour was measured using the Verbal Performance Rating Scale (22). A global assessment of cognitive, memory and perceptual dysfunction was drawn up for 14 non-aphasic patients using the Mini Mental Test (4).

Interviews were conducted with the patients, or in case of severe aphasia, with the spouse or the home-service assistant, to obtain information on: 1) use of rehabilitation, home-help and transportation services; 2) contact with a handicap organization; 3) their most relevant problem at the present time, and 4) perceived obstacles in their home environment. The interview with the spouses provided information as to their: 1) biography; 2) knowledge about stroke; and, 3) help with training at the present time, and possibly in the future.

Statistical significance of deviation from normality distribution was tested using the Shapiro & Wilk's statistics (18). The statistical significance of differences in self-reported time for different activities between males and females, aphasics and non-aphasics, and single and married individuals was assessed using the median test and the Student's *t*-test. Differences in ADL grades were tested using the median test. The Spearman rank order correlation coefficient was used to measure the association between motor function and ADL grades. Calculations were effected using the SAS statistical package (17).

RESULTS

Regarding self-reported functional capacity, the scores for personal causation, values, habits and skills as rated by each of the two observers are listed in Table I. Similar scores were given by each independent observer. The scores for all categories deviated from normality and indicated a high level of occupational functioning, except for skills which were rated slightly higher. One patient was excluded due to severe aphasia.

The number of activities for which the patients reported strong interest before stroke and no current participation, but stated they would like to pursue, are shown in Table II. Fifteen of 20 patients reported this interest pattern in one or more of the 52 activities listed. This group included most of the males, most of those living alone, and all aphasic patients.

The different activities for which 2 or more patients reported the above-mentioned interest pattern are listed in Table III. Some degree of interest was reported for 44 of the 52 activities listed. Activities for

Table II. *Number of prevalent stroke patients living at home in South-west Stockholm county, indicating different numbers of activities in which they had had strong interest before stroke, no current participation but would like to pursue*

Number of activities among 52 listed	All patients ($n=20$)	Gender		Speech function		Family situation	
		Males ($n=14$)	Females ($n=6$)	Non-aphasics ($n=14$)	Aphasics ($n=6$)	Living with spouse ($n=13$)	Living alone ($n=7$)
9–10	2	2	0	1	1	1	1
7–8	0	0	0	0	0	0	0
5–6	4	4	0	2	2	3	1
3–4	5	3	2	3	2	3	2
1–2	4	3	1	3	1	2	2
0	5	2	3	5	0	4	1

which the patients most frequently indicated strong interest before stroke and no current participation, but stated they would like to pursue were: going for rambles through the woods; swimming; home, car and boat repair; and excursions by boat. The activities the patients were able to pursue after stroke were: keeping contact with children and grandchildren (10 patients); listening to music, watching TV, reading books and the newspaper (8); lottery and doing the pools (6); playing solitaire, doing puzzles and crosswords, walking and seeing friends at home (5). Only 3 patients reported current participation in activities in which they had no interest before their stroke, namely, bingo, puzzles, solitaire, crosswords and handicrafts.

Self-reported time for different activities during an ordinary weekday is presented in Table IV. In 3 cases of severe aphasia, the questionnaire was completed with some assistance from the spouse or the home-service assistant. One aphasic patient failed to report type of activity for 1.50 hours during the day. Rest, sleep, leisure activities at home and personal care occupied most of the patients time, a mean of 19.35 hours. Daily living tasks, physical training, work and leisure activities outside the home took up the least

Table III. *Activities in which the prevalent stroke patients living at home have indicated strong interest before stroke, no current participation but would like to pursue*

Most frequent type of activities	All patients ($n=20$)	Gender		Speech function		Family situation	
		Females ($n=14$)	Males ($n=6$)	Non-aphasics ($n=14$)	Aphasics ($n=6$)	Living with spouse ($n=13$)	Living alone ($n=7$)
Roving the woods	6	5	1	4	2	3	3
Swimming	5	4	1	4	1	3	2
Home, car and boat repair	4	4	0	2	2	3	1
Excursions by boat	4	1	3	3	1	0	4
Concerts, theatre, movies	3	3	0	2	1	3	0
Driving car	3	3	0	2	1	3	0
Travelling, charter, bus tours	3	3	0	2	1	2	1
Gardening	2	2	0	0	2	2	0
Sports events	2	2	0	1	1	2	0
Participation in sports competitions	2	2	0	1	1	2	0
Hunting, fishing	2	2	0	2	0	1	1
Collector hobbies	2	2	0	0	2	2	0
Museums, exhibitions	2	2	0	1	1	1	1
Photography	2	2	0	1	1	0	2
Painting, drawing	2	2	0	1	1	0	2
Excursions by car	2	2	0	1	1	2	0
Walking	2	1	1	1	1	1	1
Arranging parties	2	0	2	2	0	0	2

Table IV. *Self-reported time use, in hours and minutes, during an ordinary weekday for all and different categories of prevalent stroke victims living at home in SWS*

Type of activity	All persons, $n=20$		Gender			Speech function			Family situation			
	Median (mean)	W statistics p-value	Males $n=14$ median (mean)	Females $n=6$ median (mean)	Median or t-test p-value	Non-aphasics $n=14$ median (mean)	Aphasics $n=6$ median (mean)	Median or t-test p-value	Living with spouse $n=13$ median (mean)	Living alone $n=7$ median (mean)	Median or t-test p-value
Rest	9.25 (9.45)	0.4536	9.50 (9.57)	8.50 (9.17)	0.3415 0.7760	9.25 (9.39)	8.75 (9.58)	0.9999 0.8593	9.00 (9.11)	10.50 (10.07)	0.6477 0.4410
Leisure activities at home	7.00 (6.45)	0.7898	7.00 (6.75)	5.75 (5.75)	0.6978 0.4898	7.00 (6.29)	6.75 (6.83)	0.5602 0.7020	7.00 (6.30)	7.50 (6.71)	0.2630 0.6974
Personal care	3.50 (3.45)	0.5286	3.75 (3.79)	3.00 (2.67)	0.0363 0.0184	3.00 (3.03)	4.25 (4.42)	0.0038 0.0042	3.50 (3.62)	3.00 (3.14)	0.6664 0.3001
Daily living tasks	1.50 (1.55)	0.0039	0.25	3.50	0.0582	1.50	0.75	0.2727	0.50	1.50	0.6664
Physical training	0.50 (0.77)	0.0004	0.50	0.50	0.7743	0.25	1.25	0.2140	0.00	1.00	0.0893
Leisure activities outside home	0.00 (1.20)	0.0001	—	—	—	—	—	—	—	—	—
Work	0.00 (1.05)	0.0001	—	—	—	—	—	—	—	—	—

amount of time, a mean of 4.57 hours, and were not normally distributed. The most frequent leisure activity at home was watching TV, a mean of 4.20 hours. Only 6 of 20 patients spent time in leisure activities outside the home, a mean of 1.20 hours. Significantly more time was reported for personal care by males than by females, with difference in means of 1.12 hours; and likewise, more by aphasic than by non-aphasic patients, with a difference in mean of 1.39 hours. A difference in time devoted to daily living tasks was found between sexes, p-value 0.058. Females spent an average of 3.25 hours more on daily living tasks than males. As shown in Table V, the majority of the patients manifested a high degree of personal causation, value and interest in most reported activities during the day. At least half the patients perceived difficulties in performing leisure activities outside the home and had little interest in performing daily living tasks.

The results for individual assessment of personal and instrumental ADL for 20 patients are presented in Table VI. Five persons were dependent in one to three personal activities and most of the instrumental activities. Five were dependent in cooking, an activity which required daily assistance, and at least two other instrumental activities. Ten were independent in both personal and instrumental ADL or only dependent in activities which did not require daily assistance, such as cleaning, shopping or using public transportation. Among those 10, 2 patients needed supervision in bathing for psychological reasons only. Two non-aphasic men, one single and one married, deviated from the ideal scale. They were independent in all personal activities and shopping, but dependent in cooking, transport and cleaning. Differences in ADL grades were found for: males vs females, medians 4 and 1, p-value 0.052; aphasics vs non-aphasics, medians 4 and 1.5, p-value 0.331; and single vs married patients, medians 1.5 and 3.5, p-value 0.331.

Six patients required a walking aid whereas 13 patients did not. One person needed both a walking aid and supervision. The scores for motor function in upper and lower extremities on the affected side, self-reported verbal performance and mental functions are listed in Table VII. The distribution of the individuals by their level in these functions is depicted in Figs. 1 and 2. The sample studied here constituted a heterogeneous group with regard to motor and speech function. Statistically significant differences from normality were disclosed for motor function in upper and

Table V. *Distribution of prevalent stroke patients living at home by degree of personal causation, values and interest when evaluating 2/3 or more of time spent in activity*

Activities	I think that I do this: well/about average or poorly	For me this activity is: important/take it or leave it or rather not do it	How much do you enjoy this activity? I like it neither like it, nor dislike it
Rest and sleep	13/7	17/3	17/3
Personal care	16/4	19/1	16/4
Daily living tasks	8/5	12/1	5/8
Work	1/2	2/1	2/1
Physical training	9/2	11/1	10/1
Leisure activities at home	16/4	16/4	18/2
Leisure activities outside home	3/3	5/1	5/1

Table VI. *Independence (i) and dependence (d) in instrumental and personal ADL for prevalent stroke patients living at home*

	Patients																			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Instrumental ADL																				
Cleaning	i	i	i	i	i	i	d	d	d	d	d	d	d	d	d	d	d	d	d	d
Shopping	i	i	i	i	i	i	i	d	i	d	d	d	d	d	d	d	d	d	i	i
Public transportation	i	i	i	i	i	d	i	i	d	d	d	d	d	d	d	d	d	d	d	d
Cooking	i	i	i	i	i	i	i	i	i	i	d	d	d	i	d	d	d	d	d	d
Personal ADL																				
Bathing	i	i	i	d	d	i	i	i	i	i	i	i	i	d	i	d	d	d	i	i
Dressing	i	i	i	i	i	i	i	i	i	i	i	i	i	i	d	i	i	d	i	i
Toileting	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	d	d	i	i
Transfer	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i
Continence	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i
Feeding	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i	i

Table VII. *Scores for motor function, verbal performance and mental function of prevalent stroke patients living at home*

	Maximum score	Number of persons	Median (range)	W statistics	*p*-value
Motor function					
Upper extremity	24	20	20 (0–24)	0.795	0.0005
Lower extremity	21	20	19 (3–21)	0.821	0.0014
Verbal performance	30	6	13 (3–24)	0.988	0.9831
Mental function	30	14	28 (25–30)	0.917	0.1967

lower extremities. Six patients also showed mild loss of motor function in the lower extremity of the non-paretic side. The Spearman correlation between total motor function scores and independence in personal and instrumental ADL was 0.40, *p*-value 0.101. Three of 6 patients had severe efferent motor or global aphasia, one moderate aphasia, and 2 minor afferent motor aphasia. For these last-mentioned 2, the ANELT scores were high: 5.0 and 4.8 for understandability and 5.0 and 4.2 for intelligibility. Cognitive and perceptual functions were, in general, preserved in all 14 patients. However, 9 patients failed the short-term memory test.

Five patients had regular contact with a day-care

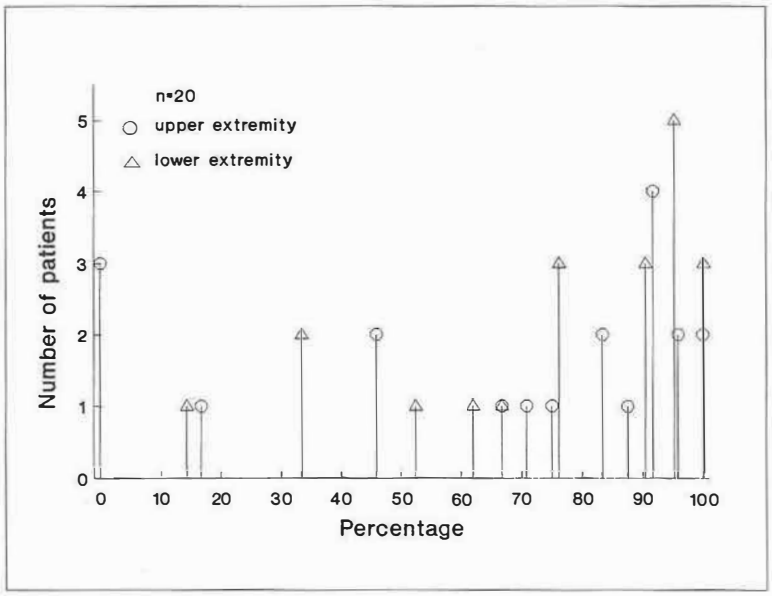

Fig. 1. Motor function in affected upper and lower extremities as percentage of maximum scores.

centre once to three times a week. Seventeen patients enjoyed subsidized transportation service. Four persons had municipal while 3 had private home-service. The amount of service received varied from twice weekly down to a couple of times a year. While 5 patients had participated in activities with a handicap organization, 12 had not but wanted to participate in the future. When patients were asked about their most relevant problem at the present time, 16 gave specific answers regarding difficulties in: leisure activities (7 patients); walking outdoors or going by bus or train (3); personal ADL (2); motor ability (2); communication (1) and personal economic situation (1). Six patients also reported physical obstacles in their home environment.

In the case of 13 patients, the potential non-

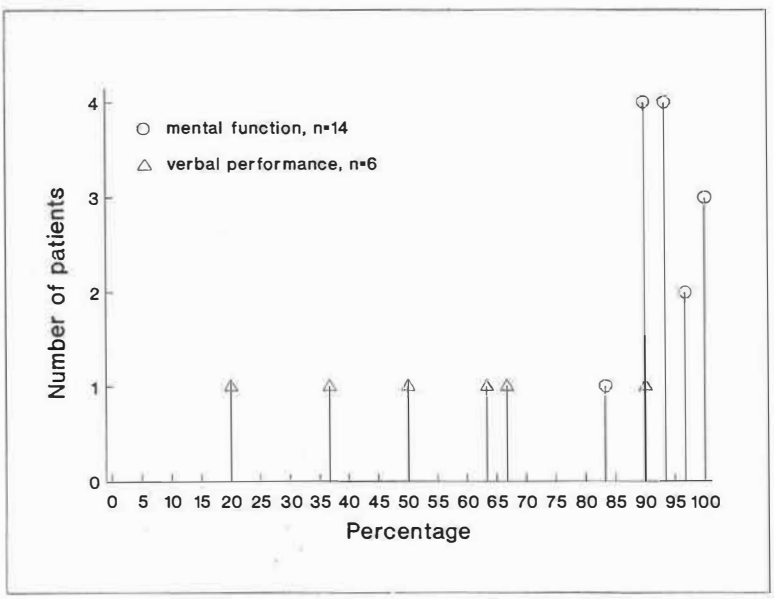

Fig. 2. Mental function and self-reported verbal performance as percentage of maximum scores.

professional assistant was their spouse, said spouse having a mean age of 67.2. Nine spouses were retired and 4 had remunerative employment. Six had attended secondary school or university and 7 had completed primary education. Ten out of 13 spouses estimated they had satisfactory knowledge of stroke as a disease. Twelve of them were involved in the training of the stroke patients at the present time; 7 through psychological support, 2 through practical support and 3 through both. Five spouses indicated that they were—and 8 that they were not—willing to increase their involvement in training. Only 2 spouses had suggestions for alternative non-professional assistants who could help with training. Two spouses have allowances for care-giving at the present time.

DISCUSSION

The occupational function profile of our sample consisted of changed activity and interest patterns but a high degree of personal causation, value and interest in most current activities during the day. These results were confirmed by two independent observers. When personal causation, values, habits and skills were considered in a US population (14), the reported scores were: 1.29, 1.28, 1.26, and 1.15 for a community group aged 60 years or more and living independently, indicating a high level of occupational functioning; and 2.78, 2.76, 3.06 and 2.78 for an institutionalized group, suggesting a significantly lower level. Except for skills, 1.97, the levels of occupational functioning in our sample were close to those of the above-mentioned elderly people living independently. Since personal causation, values and interests are correlated with life satisfaction (14), our results suggest that there is limited possibility for improving life satisfaction by rehabilitation programmes in our sample.

With regard to self-reported time for different activities, salient characteristics of our sample were the variation of the pattern among different groups and the fact that only 6 patients reported leisure activities outside the home. The fact that males and aphasics spent significantly more time on personal care could be explained by their greater dependence in ADL. Our results regarding differences between those living alone and those living with a spouse are consistent with a study which found that single members of a stroke club spent more time engaged in daily living tasks (2). More time spent on daily living tasks by women in our study could be explained by the fact that 4 out of 6 women—as against 3 out of 14 men—were living alone and had nobody with whom to share those responsibilities. In comparison with 60 subjects from a senior centre and a nursing home in the USA, mean age 78 years (14), our group spent less time engaged in sleep and rest (39% vs 47%), a similar amount in daily living tasks (21% vs 20%), and more in recreation (35% vs 27%). Life satisfaction of the above-mentioned elderly population was positively correlated with time spent on work and recreation and negatively with time spent on daily living tasks and rest. From our results it would appear that increasing the time devoted to leisure activities and decreasing the time reserved for daily living tasks could increase life satisfaction in long-term stroke survivors.

Fifteen of 20 patients reported losses in participation in leisure activities outside the home. Seven of them stated that their most relevant problem was the inability to participate in different leisure activities outside the home. Our findings are consistent both with studies which reveal declines in leisure participation for the majority of stroke patients (8, 19, 20, 21) and with those that report leisure activity and leisure satisfaction as being correlated with quality of life (14, 21). Our view agrees with that of other authors: rehabilitation programmes should focus on social and leisure activities, attempting to maintain those existing previously or adding new ones (8, 15, 19, 20). Local stroke clubs might well constitute a valuable resource for such purposes. Fifteen of 20 patients were dependent upon another person in daily living tasks such as cleaning, shopping and cooking, though none indicated that this posed a problem of any relevance to them. Hence, late therapy intervention to decrease dependence in instrumental ADL would probably not have a major impact on quality of life for stroke patients living at home. It would appear that, to be effective, appropriate rehabilitative measures should have already been implemented during the early post-acute period since: 1) most of our patients and their families may have adapted to the patients' deficits soon after stroke (20); 2) adaptive or maladaptive states in the case of chronic disability can be challenged by stressful events, including those triggered by proposed goals for rehabilitation (1); and, 3) the majority of the spouses in our sample had a limited potential for collaboration in new measures at the present time.

The small size of our sample may represent a problem when using statistical tests. Studies based on

the complete enumeration approach are, however, costly. As many patients report complete recovery (13), random samples of unselected prevalent stroke survivors may constitute an expensive non-appropriate tool for in-depth analysis of their situation and planning of stroke rehabilitation programmes. We do not feel that either the study size or the potential underlying selection, whether due to the sampling, follow-up procedure (13) or the drop-out for the home visit, can be said to undermine the usefulness of said results for planning purposes. But the results should be cautiously interpreted. Straightforward extrapolation of our conclusions to other populations where the cultural and socio-economic background or the policy for long-term hospitalization is different from that found in South-west Stockholm county should therefore be avoided.

We conclude that of stroke patients in South-west Stockholm county, living at home and interested in further rehabilitation a few years after their stroke, 3/4 had changed activity and interest patterns, 1/4 were independent in both personal and instrumental ADL, 1/2 were dependent solely in instrumental ADL, and 1/4 were dependent in both personal and instrumental ADL. Most of them had adapted to their ADL dependence and to the changes in their activity patterns, except for leisure activities outside the home. Potential improvement in quality of life of such patients could be achieved by individually-planned late-rehabilitation programmes focusing mainly on social and leisure activities outside the home. To obtain additional benefits from rehabilitation strategies, a different type of intervention might have been in order at an early stage.

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