UNIVERSITY OF GOTHENBURG

Executive dysfunctions in elderly persons with mild stroke

- Evaluation of daily activities and instrument development

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ABSTRACT

The overall **aim** of this thesis was to examine the performance of personal activities of daily living (P-ADL) related to cognitive and executive dysfunctions in elderly patients with mild stroke in the acute care and after 12 months, and to evaluate the instrument Executive Function Performance Test (EFPT) in persons with mild stroke. **Methods:** In the *first study* elderly patients with stroke (n = 60) referred to geriatric rehabilitation were included. Assessments were carried out at admission and at discharge. The median age of the group was 77 years. In the *second study* 45 of the above patients were assessed at discharge from hospital and at 6 and at 12 months after stroke onset. The Cognitive Impairment Questionnaire (CIMP-QUEST) was used to interview a close relative about the patient˝s cognitive status. P-ADL was assessed with the Barthel Index (BI), and the Mini Mental State Examination (MMSE) and a neuropsychological test battery were used to measure cognitive dysfunctions. The National Institute of Health Stroke Scale (NIHSS) was used to measure neurological deficits. Analyses were made using non-parametrical statistical methods. In the *third study* four occupational therapist raters (two pairs) made 34 assessments of patients with mild stroke in a stroke unit with the instrument EFPT to evaluate the inter-rater reliability. In the *fourth study* patients with mild stroke (n=23) from an acute stroke unit were assessed in order to evaluate the concurrent validity of the EFPT. **Results:** In the *first study* neither the presence of pre-stroke dementia nor the cognitive status after stroke onset among these elderly patients influenced P-ADL at admission or at discharge in the acute phase after stroke. In the *second study* persons with cognitive- and executive dysfunctions before and after stroke did not improve in P-ADL from the acute phase until 6 and 12 months, while persons with intact cognition pre- and post-stroke did. In the *third study* the inter-rater reliability for the EFPT was very good. The median percentage agreement was 88 %. There was no occasional disagreement between the raters. One of 20 items had a significant systematic disagreement. In the *fourth study*, the correlation between the EFPT and the AMPS assessments was highly significant and the concurrent validity was moderate. **Conclusion**: Neither the presence of pre-stroke dementia nor the patient˝s cognitive status after stroke onset showed any impact on P-ADL or independence in the acute phase after stroke. After 12 months, however, a relation was shown between P-ADL and cognitive and executive dysfunctions. These findings may indicate that the recovery of P-ADL in elderly patients after stroke is influenced by more factors than cognition or that assessment of P-ADL does not always detect cognitive dysfunctions. The results demonstrate the importance of using more complex activities in assessing the patient˝s activity status since executive dysfunctions are more easily detected in tests with instrumental activities in daily life. Since there is a risk that some patients

with mild stroke will be discharged without any rehabilitation, and occupational therapists have up till now lacked a relevant instrument for detecting problems with executive skills in acute stroke care, it is suggested that the EFPT is a suitable instrument for use in these patients.

Keywords: Acute stroke, Cognitive dysfunction, EFPT, Elderly, Executive dysfunction, Instrumental Activities of Daily Life, Mild stroke, Personal Activities of Daily Life, Translation

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I. Cederfeldt M, Gosman-Hedström G, Sävborg M, Tarkowski E.

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Arch Gerontol Geriatr 2008:49:118-122.

II. Cederfeldt M, Gosman-Hedström G, Gutierrez-Perez C, Sävborg M, Tarkowski E.

Recovery in personal care related to cognitive impairment before and after stroke – a 1-year follow- up.
Acta Neurol Scand 2010: 122: 430-437

III. Cederfeldt M, Dahlin-Ivanoff S, Carlsson G, Gosman-Hedström G.

Inter-rater reliability and face validity of the instrument Executive Function Performance Test (EFPT).
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IV . Cederfeldt M, Widell Y, Elgmark-Andersson E, Dahlin-Ivanoff S, Gosman-Hedström G.

Concurrent validity of the Executive Function Performance Test (EFPT) **in persons with mild stroke.**
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CONTENTS

ABBREVIATIONS

AMPS	Assessment of Motor and Process Skills
BI	Barthel Index
CIMP-QUEST	Cognitive Impairment Questionnaire
CT	Computer Tomography
EFPT	Executive Function Performance Test
ESO	European Stroke Organization
I-ADL	Instrumental Activities of Daily Living/Life
IQCODE	Informant Questionnaire on Cognitive Decline in Elderly
MMSE	Mini Mental State Examination
NIHSS	National Institute of Health Stroke Scale
P-ADL	Personal Activities of Daily Living/Life
PA	Percentage Agreement
ROC	Relative Operating Characteristic
RP	Relative Position
RV	Relative Rank Variance

Introduction

Studies about stroke have mostly focused on mortality and lifelong physical disabilities (1). In the last decade, however, the focus has also been on cognitive dysfunctions and their consequences on activities of daily living, which include all goal-directed activities, such as self-care, household activities, productivity and leisure (1). Being dependent on others and losing control of performance in activities of daily living may be frustrating for persons who have suffered a stroke, since such activities are related to their personal identity and feelings of independence , which are linked to being able to do things when they choose to do it (2). Stroke is a major public health problem in the Western world, and in Sweden it is the third major cause of death after ischemic heart disease and cancer and the most common cause of permanent disability (3). The incidence in Sweden is approximately 30 000, and 80 % of those are older than 65 years. The diagnosis stroke accounts for almost one million hospitalizations and the largest number of days in healthcare. The total cost of stroke care is about 14 billion SEK a year. Of the 30 000 persons affected, two-thirds had stroke for the first time(3, 4). The mean age for stroke onset is 75 years (73 years for women and 77 years for men).Since occupational therapy as a discipline focuses on activities of daily living (ADL), it is important to evaluate the relation between cognitive dysfunction and ADL as a basis for assessment and intervention.

Activities of daily living and cognitive function in a population of normal aging

It has been reported that thirteen per cent of the elderly persons who were 76 years old received personal assistance in Personal Activities in Daily Life (P-ADL) and 22 % in Instrumental Activities of Daily Living (I-ADL) (5).The I-ADL that has been shown to be most common to need assistance with were cleaning, cooking and shopping (6). One study has shown that the cognitive dysfunctions that have a negative impact on elderly persons ($\geq$ 60 years) are related to: attention (selective, divided and to change focus), executive functions, the explicit memory (retrieval of the memory), working memory, episodic memory (memory related to time and space), tempo and learning (7). The loss of such cognitive functions naturally has a negative impact on aging, but it should be borne in mind that the preservation of cognition in the elderly population varies. Before reviewing the relation between ADL and cognitive dysfunctions in

elderly patients after stroke, it is important to understand the definitions of the concepts cognition and executive dysfunction.

Cognition and executive dysfunctions in elderly patients after stroke

Studies have shown that elderly patients after stroke had a high frequency of cognitive dysfunctions both before stroke, in acute care (8) and in the long run (9). In the present studies in the thesis (I-IV) the acute care phase is defined as the time from the onset of stroke until the patient is discharged from the hospital. Cognition may be divided into four major classes: *receptive functions,* which involve the abilities to select, acquire, classify, and integrate information; *memory and learning,* which refer to information and retrieval; *thinking,* which concerns the mental organization and reorganization of information; and *expressive* functions, which are the means through which information is communicated or acted upon (10). Another definition is the person"s capacity to acquire and use information to adapt to environmental demands which encompasses information-processing skills, learning and generalization (11). According to Toglia (11) p.29, "cognition is not divided into separate subskills such as attention, memory and organization . Instead, cognitive abilities and dysfunctions are analysed according to underlying strategies, ability to monitor performance and potential learning". Toglia emphasizes that cognition is not static, stable or fixed; it changes with our interaction with the external world. This means that cognition is modifiable under certain conditions (11).

Studies have also shown that executive dysfunctions are common in elderly patients after stroke (11-14). Executive functions are closely related to cognition and is defined as the ability to formulate realistic goals based on stored plans and to develop strategies in flexible problem solving (15). Executive functions may be defined in different ways, but the concept is a psychological construct (16). The key components in executive functions according to neuropsychologists (16) are anticipation, attention, impulse control, self regulation, initiative, working memory, mental flexibility, utilization of feed-back, planning, organization, selection of problem-solving strategies. Traditionally, the short-term memory was described as a temporary memory which could only hold a small amount of information before it became permanent in long-term memory (17). But in the 1970s this concept expanded to refer to a more active memory system called the working memory. The working memory has two information canals, one from

sensory memory and one from long-term memory. The working memory integrates verbal, visual and spatial information on both new and old memories over a short period of time before passing the long-term memory (17). Patients with executive dysfunctions may be unable to keep track, to plan, to organize, to reason, and to shift between conflicting demands (16) .

The difference between executive and cognitive functions is that executive functions refer to *how* and *if* a patient performs an activity (e.g. Will you do it ? If so, how and when ?), while cognitive functions refer to *what* a patient performs and *how much* he/she performs it (e.g. How much do you know ? What can you do?) (18). If the executive functions are intact, a patient with impaired cognition can still be independent, but if the executive functions are reduced, it is not certain that he/she has the ability to be independent in ADL or maintain social relations how well his/her cognitive functions are preserved or regardless of how high the results of his/her cognitive tests are (10). Executive functions are important when a patient wants to adapt to a new situation, but they are also the base for several cognitive, emotional and social skills (10, 19). A study (19) has shown that post-stroke persons (55-85 years) with executive dysfunctions were often in the upper age range, had a lower level of education, more often had dementia, had generally impaired cognitive functions, and were more depressed than elderly post-stroke persons without executive dysfunctions.

Executive functions also refer to metacognition. The definition of metacognition is a person‟s belief and knowledge about his or her own cognitive processes or „knowing what you know“(17). With metacognition we are able to monitor our behaviour or to evaluate our decisions. The executive functions are closely related to awareness in metacognition. Loss of awareness results in an inability to find errors in performance or to plan strategies. The executive functions which also are metacognitive act as a control system for self-monitoring and self-guidance (17).

P-ADL and cognitive and executive dysfunctions in the acute phase and in the long run

There is no clear evidence in the literature if P-ADL is influenced by cognitive dysfunctions in the acute phase in elderly patients after stroke. A fair number of studies (20-24) still show contradictory results. No study included only patients from > 65 years (20-24). There are also contradictory results (13, 24-29) regarding how cognitive dysfunctions influence P-ADL in the long term (6-12 months after stroke). There is still a lack of studies that have investigated patients

with cognitive dysfunctions before stroke onset and their recovery in P-ADL in the acute phase and in the long term.

One study (13) evaluated the association between executive dysfunctions and P-ADL in the acute phase and found that 89 % of the patients with executive dysfunctions were dependent in P-ADL while 50 % of the group had intact executive functions (13). There is still no study describing how cognitive and executive dysfunctions influence P-ADL in the acute and long term.

I-ADL and executive dysfunctions in the long run for elderly persons after stroke

Studies have demonstrated an association between reduced ability in instrumental activities and executive dysfunctions in elderly persons 2-3 months after stroke (19, 30, 31). Even mild executive dysfunctions, such as deficit in attention, have led to problems in I-ADL (32). Reduced social participation by persons 6 months after discharge from the stroke unit has been shown to be associated with executive dysfunctions (30). However, according to some neuropsychological literature, there may be a problem when assessing executive functions with neuropsychological instruments. Miyake et al (33) pointed out that it is no clear consensus on how to best measure executive functions with neuropsychological tests. Dawson et al. (34) emphasized that conventional executive function assessment is done at the impairment level and is unable to capture the complexity in ADL. Therefore accurate tests assessing the influence of executive skills on instrumental activities among post-stroke patients in acute care are still lacking. Before focusing on assessing executive functions with ADL some theoretical frameworks of executive functions will be described from a neuropsychological perspective to better understand the psychological construct.

Neuropsychological perspective and theoretical frameworks

Neuropsychological models are theoretical frameworks for the assessments of cognitive domains. No model has been uniformly accepted, and even the assumptions differ (16). There are several theoretical models of executive functions such as: the Supervisory Attentional System (SAS), the Working Memory Model, the Model of Executive (self-regulatory) Functions, the Components of Executive Functions, the Problem-solving Frameworks and the Executive Control System. These

models focus on different aspects of executive functions such as attention, working memory, self-regulation and problem-solving (16). In conclusion, none of the neuropsychological models focuses on the individual in his/her context with all the routines/habits, roles and goal-directed activities. According to occupational therapy perspective (35-37) these above factors may influence a person"s performance in ADL why an occupational therapy perspective may be a complement to the neuropsychological frameworks in assessing executive functions in patients with mild stroke.

Theoretical models on assessing cognition and executive dysfunctions in occupational therapy

Occupational therapy strives to promote health and well-being through occupations. Occupation can be defined, according to Law and Baum (37), as everything that we do in life including actions, tasks, activities, thinking and being. Engagement in occupation describes the interactions of the individual with their self-directed life activities. The primary goal of occupational therapy is to enable people to participate successfully in the ADL. Occupational therapists achieve this by enabling people to do things that will enhance their ability to live meaningful lives, or by modifying the environment to better support participation (38). To enable people to perform activities, the occupational therapist has to know how to do this in different ways in order to give the patients the most accurate assessment and introduce the most appropriate interventions. There are several theoretical models in occupational theory that describe different aspects/factors that may have an impact on a person"s ADL performance. To achieve the goal of occupational therapy it is valuable to understand these factors, and cognitive dysfunction may be one of them.

One study has shown that cognitive functions measured with cognitive tests actually have a negative influence on elderly persons (39). The psychometric tests, which measured executive functions and memory, did not always correspond to elderly people"s ability in everyday life. Despite the fact that younger persons achieved better results than elderly people on these tests, both the groups solved the problems in everyday life equally effectively (39). One explanation was that elderly persons have a larger experience memory to choose from and more routines, and that they can get help from contextual factors just as well as younger persons (39). This finding emphasizes the importance of assessing patients after stroke through observing their ADL (28) to

get a realistic view of the patient‟s performance in ADL. Most of the theoretical models of occupational therapy (35-37) show that the environment is an important factor in occupational performance. Even if the assessment is an observation in activities in daily living, it is important that the complexity of the activity may discover what kind of cognitive problems the patients have. Since P-ADL imply basic activities in daily life consisting of routines that people have performed since childhood, they do not always require so many problem- solving functions. In occupational therapy there is an instrument, the Assessment of Motor and Process Skills (AMPS) (40) that is suitable for assessing executive skills/occupational performance in instrumental activities (41). It has been emphasized that occupational therapists should focus on how executive skills relate to occupational performance and may use the AMPS to make a detailed analysis of a person‟s executive dysfunctions (41). Unsworth (41) pinpoints the different steps in the executive functions and how they relate to activities in the AMPS such as: *heeding, planning*, c*hoosing, take initiative, sequencing, continuing and termination.* However, although AMPS is a valid, reliable and widely used instrument (42-46), it involves an advanced assessment that requires a special course for training, and the raters have to be recertified if they do not assess with the AMPS within one year. The assessment also requires enough patients‟ observational time. Even if the AMPS is a valid and reliable instrument, it is not always easy to use it in the acute care due to the detailed assessment. The AMPS require every activity recorded to be performed exactly as it is described in the manual. Since there are 83 activities, it is impossible to learn them by heart. With the AMPS the patient should preferably be assessed in an activity that he/she is used to doing. This may be a problem since the executive skills are mostly needed in novel activities.

A rather new approach in occupational therapy is the dynamic interactional approach to cognitive rehabilitation introduced by Toglia (11). The model emphasizes the processes of change and learning, for example, using cues in the assessment. In this model self-awareness and processing strategies (attention, memory, organization and problem solving) are core concepts (11), and cognition and performance change with experiences and the interaction between the person, the activity and the environment. This means that cognitive ability differs in different situations and one may take into consideration that several factors that may influence the performance.

Occupational therapists' assessment of executive dysfunctions in acute care

In the Western world today, it is important to assess executive dysfunctions in the acute stroke care of elderly patients as the length of stay for these patients on the acute wards is decreasing (47). However, most instruments in acute care focus on assessing personal care. This is a problem since more complex activities such as I-ADL may be the best ones for detecting executive dysfunctions (10, 13, 19, 30, 31).

Another problem regarding assessing executive dysfunctions is that occupational therapists often assess patients in activities that they are used to doing. This may be a problem since executive dysfunctions often are detected in novel activities that the persons have not done before (48). Therefore an instrument with novel activities may be the best one for occupational therapists to use in acute care. There is evidence that persons have problems with I-ADL in the acute phase after stroke (49). It has been emphasized that it is important to assess executive function in naturalistic activities, since even if a person after stroke does not show any cognitive dysfunction in cognitive test, they may still have problems with executive functions (18). It is therefore important to find a valid and reliable instrument, which is easy to handle in acute care, for assessing executive functions in relation to I-ADL.

The instrument Executive Function Performance Task (EFPT) (50) was introduced into Sweden recently aimed to assess executive functions through I-ADL and to determine the level of support needed to become as independent as possible in I-ADL. It originated in the USA and has three purposes a) to determine which executive functions are impaired b) to determine an individual"s capacity for independent functioning and c) to determine the amount of assistance necessary for task completion. The EFPT is used to assess the performance of activities that are essential for self-maintenance and independent living. Law and Baum (37) defined occupation as everything that we do in life including actions, tasks, activities, thinking and being, One might say, for example, that in the EFPT grasping a spoon and making a circular movement with it in preparing oatmeal porridge is the same as an action, making porridge for breakfast is the same as a task and the activity is to make the whole breakfast.

The executive dysfunctions in the test refer to deficits in initiative, organization, sequencing, judgement and safety and completion. To perform an activity with the above tasks in the EFPT, a

person needs functions such as anticipation, attention, impulse control, self regulation, initiative, working memory, mental flexibility, and utilization of "feed back", planning, organization, selection of efficient problem-solving strategies and self awareness (16). The activities in the EFPT should not be strong habits in the patient, but the task selected should be a goal-directed activity that should preferably be meaningful for the patient. The instrument also meets the criteria for the new assessment trend in occupational therapy, which focuses on the dynamic interactional approach with cues in the assessment procedure (11). The validity and reliability of the instrument EFPT had been tested in the United States in patients with mild stroke (48) but needed to be tested under Swedish conditions.

Overall aim:

To examine the performance of P-ADL related to cognitive and executive dysfunctions in acute care and in the long run and to evaluate the instrument Executive Function Performance Test in patients with mild stroke in the acute care.

The specific aims were:

- To examine how pre-stroke dementia and cognitive dysfunction after stroke influence P-ADL in elderly persons in the acute phase after stroke (Paper I).

- To examine longitudinally
  1) whether there were any differences in the recovery in performance of P-ADL in elderly persons in relation to cognitive- and executive dysfunctions pre- and post stroke from discharge to 6 and 12 months after stroke onset
  2) and if there were any differences in executive dysfunctions after stroke at acute care and after 12 months (Paper II).

- To examine the inter-rater reliability and the face validity of the new instrument EFPT assessing instrumental activities in acute care in patients after stroke with mild stroke (Paper III).

- To examine the concurrent validity of the EFPT in acute care in patients with mild stroke (Paper IV).

METHODS

The thesis is based on four studies (I-IV) (Table 1). The first two studies (I-II) were based on the same study population, and the drop- outs are shown in figure 1. The median age of the populations in studies I-IV were from 73-84 years.

Table 1. Overview of the studies in the thesis including the population, the design and the data collection.

	Study population	Study design	Data collection
Study I	Elderly patients with stroke (n=60)	Cross-sectional study in the acute phase	Observation and interview of the P-ADL Questionnaire about cognitive dysfunctions. Measurements of cognitive functions
Study II	Elderly persons with stroke (n=45)	Longitudinal study- follow up after one year	Observation and interview of the P-ADL Questionnaire about cognitive impairments Measurements of cognitive functions
Study III	Senior occupational therapist raters (n=4) made assessments (n=34) on 17 patients	Inter-rater reliability study in the acute phase. Face validity and translation procedure	Observation of the I-ADL
Study IV	Adults patients with mild stroke (n=23)	Concurrent validity study in the acute phase	Observation of the I-ADL

Studies I-IV

The characteristics of the study populations are shown in table 2, which also includes the assessment phase and the median of the BI (51) at discharge.

Table 2. Overview of the studies in the thesis including the median of age, the range, the gender, the inclusion criteria, what mild stroke is based on, the assessment phase, the frequency of mild stroke, the median of the Barthel index (BI) and percentage of patients discharged to own home.

	Study I	**Study II**	**Study III**	**Study IV**
Median of age	77	76	84	73
Range years	(65-92)	(65-91)	(69-98)	(48-86)
Female	47 %	40 %	53 %	30 %
Inclusion Criteria	65 years old at stroke onset, with acute brain infarction or hemorrhage	65 years old at stroke onset, with acute brain infarction or hemorrhage	Person with mild stroke and over 65 years old	Person with mild stroke and from 48 years of age
Mild stroke is based on	NIHSS from 0-6 points	NIHSS from 0-6 points.	NIHSS from 0-6 points and BI ratings 50-100.	BI ratings 50-100.
Assessment phase	Acute phase	Acute phase to 6 and 12 months	Acute phase	Acute phase
Mild stroke at the acute care	78 % at admission	87 % at discharge	100 % at admission	100 % at admission
Median of BI (0-100) at discharge	80	80	100	100
Discharged to own home	75 %	82 %	94 %	100 %

Inclusion criteria for the raters in study III were; actual working at a stroke unit and willing to participate in the study. The four raters, occupational thera, were aged between 26 and 50 years. All four were women, and they had worked with stroke patients for 1.5 - 5 years. They had worked as occupational therapists from 2 - 8 years.

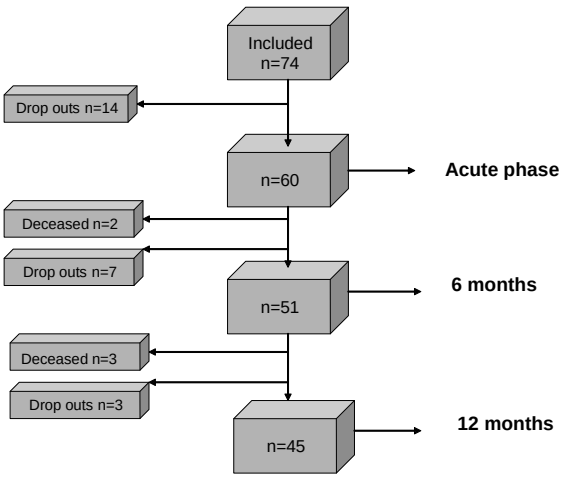

Figure 1. Flow chart of the patients‟ adherence to the studies

Instruments in the studies

The instruments used in the studies are shown in table 3. In studies I and II, the neuropsychological instruments were used to measure cognitive functions in detail. In studies I-IV, the BI (51) was used to assess P-ADL. In studies I-II and IV, the National Institute of Health Stroke Scale (NIHSS) (52)was used to measure the severity of stroke. In studies III-IV, the EFPT (50) was used to assess the amount of support the patients needed in I-ADL and what kind of executive dysfunctions that were impaired. In study III the AMPS (40) was used to assess the quality of performance of I-ADL. The different instruments are described in more detail in the separate studies.

Table 3. Instruments used in the studies and what they measure.

Instruments	**Study I**	**Study II**	**Study III**	**Study IV**	**What do the instruments measure ?**
Barthel Index **(BI)** (51)	X	X	X	X	Performance of P-ADL & classify the severity of stroke
National Institute of Health Stroke Scale **(NIHSS)** (52)		X	X		The severity of stroke
Neuropsychological instruments					
Cognitive Impairment Questionnaire **(CIMPQUEST)**(53)	X	X			Cognitive functions
Mini Mental State Examination **(MMSE)** (54)	X	X			Global cognitive functions
Wechsler´s logical Memory test **(WLM)** (55)	X	X			Auditive memory
Cronholm-Molander (56)	X	X			Visual memory
Count number of cubes (57)	X	X			Visuospatial function
Copy cube (58)	X	X			Visuospatial function
Draw mirror image of a cup (57)	X	X			Visuospatial function
I-flex (59)	X	X			Executive function
Trail making test A **(TMT)** (60)	X	X			Speed and attention
Raven"s coloured matrices (61)	X	X			Logical deductive ability
Stroop test (62, 63)	X	X			Visual impulse control
Occupational therapy instruments					
Assessment of Motor and Process Skills **(AMPS)** (64)				X	The quality of performance of I-ADL
Executive Function Performance Test **(EFPT)** (50)			X	X	The amount of support the person needs in I-ADL

The Barthel Index (BI) (51) was used to assess performance in P-ADL and to define mild stroke. Mild stroke was classified as a BI score from 50-100 (1) in studies III and IV. The BI consists of ten items: i.e. feeding, moving from wheelchair to bed and returning, personal toilet, getting on and off toilet, bathing self, walking on a level surface, ascending and descending stairs, dressing and undressing, controlling bowel and controlling bladder. Each item contains two to four levels of dependence, and the rater produces a sum score, in which 100 points refers to total independence, and the degree of assistance needed is rated from 0 to 95. The BI has been tested for validity and reliability (65, 66).

The National Institute of Health Stroke Scale (NIHSS) was used to score the patients" stroke severity, in the area of consciousness, visual fields, facial palsy, motor strength, ataxia, sensory system, language, dysarthria and inattention (sensory neglect). Mild stroke was scored from 0 to 6, moderate stroke scored from 7 to 13, and severe stroke scored from 14 to 38 (52). Validity has been tested in patients with stroke (52).

Cognitive Impairment Questionnaire (CIMP-QUEST) (former Åstrand"s questionnaire) (53) is a questionnaire for the next of kin to rate the patient"s cognitive status. The aim of CIMP-QUEST is to focus on cognitive functions with regard to how the patient behaved in his/her practical and social life. The questions in CIMP-QUEST are based on cognitive functions in relation to the frontal lobe (10 questions), the parieto-occipital lobe (10 questions), subcortical structures (10 questions) and specific memory functions (seven questions). The dementia diagnosis was stated according to the CIMP-QUEST and DSM-III (67). A recent study (53) has shown that CIMP-QUEST has high reliability and validity in patients with mild cognitive dysfunction and mild dementia.

The Mini Mental State Examination (MMSE) (54) measures attention, arithmetic, memory, orientation, language and spatial function. The aim of MMSE in the present study was to measure global cognitive functions in a screening test to find out if there were any differences from the neuropsychological tests that measure cognitive function in detail. The cognitive dysfunctions were defined to the standard cut-off as a score below 24/30 points, and patients with an MMSE

score of less than 18/30 were considered to have severe cognitive dysfunctions (68) . The MMSE has been validated in patients with stroke (69).

The Neuropsychological Battery consisted of different tests where the aim was was to measure various cognitive domains in detail (Table 3). Cognitive functions were dichotomized as impaired and intact functions, and the patient was considered to have intact cognition when all subtests were correctly performed. A recent study (53) showed that the construct validity of the Trail Making Test (TMT), Wechsler‟s Logical Memory (WLM), Stroop test, I-Flex and Ravens matrices differed significantly between a group of elderly patients after stroke and a control group (8). The Cronholm-Molander has been tested for different groups of age (56), and visuospatial functions such as copying cubes, counting the number of cubes and drawing a mirror image of a cup were tested with Luria‟s Neuropsychological Investigation, which is frequently used (57).

The Assessment of Motor and Process Skills (AMPS*)* was used as the gold standard to measure the concurrent validity of the EFPT. The AMPS consists of 83 activities primarily in I-ADL which have different levels of difficulty. All the activities are standardized, and the patient chooses two activities that he or she is used to doing, but which also provide a certain challenge for the patient. The AMPS also supplies a profile of motor and process skills that limit and support I-ADL performance. The ADL motor skills are: body position, obtaining and holding objects, moving self and objects and sustaining performance (consisting of 16 different skills). The process skills are: applying task knowledge, temporal organization, space and objects and adapting performance to the situation regarding the environment and the behaviour (consisting of 20 different skills) (40). An experienced occupational therapist observes and assesses the quality of I-ADL performance (in all the 36 skills) according to a 4-level scale, ranging from 1 (difficulties) to 4 (competent). It has been concluded that “The AMPS process skill scale can discriminate between individuals who are able to live independently in the community and those who would require assistance. Of persons with ADL process ability measures below 1.0 logit, 93 % required assistance to live in the community ” (40) p.214. The raw score, which is ordinal, is converted into a linear score with the Rasch analysis (40). Several studies have investigated the

validity of the instrument (40, 42, 45, 46). One study (42) that evaluated if there was a difference in process skills between patients having brain damage on the right and those with left-side damage showed that there was no statistical difference in the performance of activities. The instrument has also been compared with neurological tests, and the correlations were found to vary from a moderate to weak association between the level of activity and cognitive functions (44, 46).

The Executive Function Performance Test (EFPT) (70) was used to evaluate face validity, concurrent validity and inter-rater reliability. The EFPT assesses executive functions in four tasks. Every task (simple cooking, telephone use, medication management and bill payment) has five items: initiation, organization, sequencing, judgment and safety and completion, defined as the executive functions. In every executive dysfunction, five levels of cueing can be supported by the occupational therapist in relation to the amount of cueing the patient needs, as a part of intervention. The levels of cueing or guidance are 0 (no cue required); 1 (indirect verbal guidance); 2 (gestural guidance); 3 (direct verbal assistance); 4 (physical assistance); 5 (do it for the patient). There are also pre-test questions about the patient‟s awareness of what kind of activities he or she is used to doing at home and if the patient knows whether he/she will be able to perform the task. No special course of training in the use of the instrument is required, but there are detailed instructions in the EFPT test protocol (70). A higher score reflects a need for more cueing and also demonstrates more severe problems with executive dysfunctions. The maximum score is 25 points for each task. The maximum score for each executive function is 5, which implies that the maximum score for the same items (for example, initiative) in all four tasks is 20 points. One study by Baum et al. (48) has investigated the validity and reliability of the instrument for patients after mild stroke and showed that the construct validity of the EFPT could discriminate between mild and moderate stroke and health controls. The study also showed that the inter-rater reliability and internal consistency indicated high levels of correlation, and that the criterion validity regarding neuropsychological measures had lower levels of correlation than activities in daily life. Furthermore, according to P-ADL, the criterion validity was significantly lower than the instrument assessing instrumental skills (48).

Procedures

Studies I-II

The patients‟ P-ADL was assessed by observation with the BI at admission and discharge by two assistant nurses, and a nurse interviewed the patients and next of kin at the geriatric stroke unit regarding the pre-stroke P-ADL status. The same nurse assessed P-ADL through interview at 6 and 12 months after stroke onset either at the polyclinical setting or in the patient‟s home. The CIMP-QUEST was introduced at the clinic by the same nurse to a close relative of the patients at the geriatric stroke unit during the acute phase and after 12 months. The close relatives filled in the pre-stroke cognitive status of the patient in the questionnaire at home and sent it back to the geriatric stroke unit during the acute phase and after one year. Two senior physicians used the CIMP-QUEST as one of two assessments when stating the dementia diagnosis pre-stroke. The same nurse measured cognitive functions with the MMSE during the acute phase at the geriatric stroke unit and in the polyclinical setting or in the persons‟ home at 6 months and at 12 months after stroke onset. The same neuropsychologist measured cognitive functions with a neuropsychological battery during the acute phase at the geriatric stroke unit and at 12 months after stroke onset at the polyclinic or in the persons‟ home. Eighty- seven per cent of the persons were able to come to the polyclinic at 12 months, and 13 % of the patients were assessed at home. The same physician measured the stroke severity with the NIHSS at the acute phase and after 12 months after stroke.

Study III

The evaluation of the inter-rater reliability was done by four occupational therapists trained to use the EFPT instrument to assess the patients. They formed two pairs, and each pair assessed a patient at the same time. One of the pairs assessed 13 patients, and the other pair four patients. All patients were assessed at the clinic in the first week. The raters alternated when giving the instructions to the patients. The patients received written information about the study and had to sign a form showing that they had consented to participate. The *translation* of the EFPT included three phases. Initially, the first author (MC), whose primary language was Swedish, translated the EFPT from English into Swedish. The second phase was a back-translation done by an

independent professional translator (GT), whose primary language was English (71). In the third phase, the first author assessed the equivalence between the translation and the source document and discussed discrepancies with the professional translator.

The evaluation of *face validity* (12) started with an expert group experienced in stroke rehabilitation from three geriatric rehabilitation wards from three hospitals. The expert group answered structured questions about the clinical utility of the EFPT for the diagnosis stroke, such as the time used, the cultural relevance and the clarity of the information in the EFPT. This was an unpublished pilot study. Another expert group with experience of acute stroke settings discussed the semantic equivalence of the Swedish language of the EFPT. After the group discussion, some of the instructions were made clearer.

Study IV

To evaluate the concurrent validity, all patients were assessed the first week after admission at the clinic with both the EFPT and the AMPS, by a senior reg. occupational therapist (YW) trained in the use of the EFPT and certified and calibrated in the AMPS. To avoid assessing all patients with the same instrument at the first assessment, patients born on an even date started with the EFPT assessment and patients born on an odd date started with the AMPS. The study group had chosen 13 different instrumental activities from the AMPS with different levels of difficulties (table 9). The assessments were preferably performed on the same day if possible (n=7), within two days (n=11), within three days (n=4) and within five days (n=1).

Statistical analysis in the studies

The nonparametric tests Wilcoxon Sign Rank Test and Mann Whitney were used for group comparison. Chi-square was used for nominal data (72). The non-parametric test Spearman"s rank correlation was used for correlation between the BI and the MMSE and between the AMPS and the EFPT. $P<0.05$ and $P<0.01$ was considered statistically significant. Both one- and two-sided significance were used. For demographic data mean, standard deviation, medians, quartiles and range were used. Percentage agreement (PA) was used to measure agreement between the raters (73, 74). To evaluate if there were any systematic and/or occasional components in the observed disagreement between the raters, a rank-transformable statistical approach was used

(73, 74). The distribution of paired assessments of each item was evaluated by means of a contingency table. Dispersed observations in the contingency table are a sign of occasional disagreements. The Relative Rank Variance (RV) is a measure of occasional disagreement. Possible values of RV range from 0-1. The higher the RV is, the larger the occasional contribution to the observed disagreement (73, 74) is. The presence of systematic disagreement in paired assessments is measured by Relative Position (RP). RP can be illustrated in a Relative Operating Characteristic (ROC) curve. A convex or concave ROC curve demonstrates systematic disagreement. Possible values of RP range from -1 to 1, and zero values indicate a lack of systematic disagreement(73, 74).

ETHICAL CONSIDERATIONS

The studies I and II were approved by the Ethics Committee at the Faculty of Medicine at the University of Gothenburg (S 577-01). Studies III-IV were approved by the Regional Ethics Committee in Gothenburg (Dnr.272-09). All participants in the study group agreed to participate in the study after both oral and written information. The ethical problem that might be perceived in the studies is that the patient may experience that he or she is completely recovered at the hospital, since the environment at the hospital does not make great demands on the patients as it does when the patient returns home, which might mean that he/she does not really know how important the assessment is. The advantage of the assessment is that it may prevent problems for this patient group since interventions can start before they are discharged or before a referral is sent to a rehabilitation team in the patient‟s home environment. Another ethical problem may be when the next of kin answered questions about the cognitive status of the patient. Here it is important that the patient gave the next of kin permission to answer these questions. Even if the patient approved this contribution of the proxy, there may be an ethical dilemma.

RESULTS

Study I

Influence of Cognition on P-ADL in the Acute Phase

The main findings in the present study were that there were no significant differences regarding BI between patients with and without cognitive dysfunctions at admission and at discharge when the cognitive functions were measured in detail. Regardless of cognitive status in the acute phase, all patients except the patients who had intact *speed and attention* improved significantly in all functions, measured in detail by a neuropsychologist. In the acute phase after stroke, neither the presence of pre-stroke dementia nor the cognitive status after stroke onset among these elderly patients influenced P-ADL at admission or at discharge.

The study showed that all patients in the study improved significantly in P-ADL from admission to discharge. The groups comprised patients with and without pre-stroke dementia, and patients with and without cognitive dysfunctions at admission to the geriatric ward. Regarding the cognitive functions that are included in executive functions such as: visual memory, logical deductive ability, mental flexibility, visual impulse control, verbal impulse control and speed and attention, the results showed that the patients had a high frequency of problems with these functions, i.e. from 31 -74 %. In the study group (n=60), 70 % had had paresis and 57 % had had a stroke previously, which made the group more vulnerable than a group which had stroke for the first time. According to MMSE, 40 % of the group had cognitive dysfunctions at the acute phase and 25 % had pre-stroke dementia.

Study II

P-ADL and cognitive status from the acute phase to 12 months after stroke

Thirty-one per cent of the study group (n=45) were dependent in P-ADL before stroke. At discharge, 29% were independent in P-ADL and at 12 months 42%. In the acute phase, 29% had cognitive dysfunctions as measured with MMSE, 10% at 12 months. The characteristics of the persons in study II are shown in table 4.

Performance of P-ADL improved significantly between discharge and 6 months and between discharge and 12 months in the study group (n=45). When the cognitive status of the patient was

assessed with neuropsychological tests, 91% had cognitive dysfunctions at the acute phase and 77% at 12 months. The different cognitive dysfunctions are shown in table 5.

Table 4. Longitudinal characteristics of the persons in the study (n=45*): pre-stroke cognitive status, neurological status and living conditions at discharge, at 6 months and 12 months after stroke (Study II)

	Discharge (n / total)	**%**	**6 months (n / total)**	**%**	**12 months (n/ total)**	**%**
Age (median)	76 years					
(range years)	(65-91)					
Women	(18/45)	40				
Compulsory school	(34/45)	76				
University school	(3/45)	7				
Living at home	(37/ 45)	82	(40/45)	89	(40/45)	89
Assisted living	(18/ 45)	40	(18/45)	40	(5/45)	11
Living alone	(22/ 45)	49	(22/45)	49	(22/45)	49
Pre-stroke cognitive dysfunctions	(18/ 41)	44				
Mild stroke [1]	(25/32)	78			(39/ 45)	87
Moderate stroke[1]	(7/32)	22			(6/ 45)	13
Severe stroke [1]	(0/32)	0			(0/ 45)	0
Paresis [2]	(31/ 44)	70	(9 /44)	20	(11/44)	25
Sensory	(17/ 44)	39	(15/44)	34	(13/44)	30

* There are different numbers of persons due to internal drop-outs.
1. Classified according to The National Institute of Health Stroke Scale (NIHSS)
2. Paresis in one or two extremities.

Table 5. Percentage of persons (n=45*) that had cognitive dysfunction in acute care and at 12 months after stroke onset.

	Acute Phase		12 Months	
Cognitive dysfunctions	%	(n)	%	(n)
Visual memory (n=43)	35	(15)	49	(21)
Auditive memory (n=41)	34	(14)	39	(16)
Logical deductive ability (n=41)	51	(21)	61	(25)
Visuospatial perception (n=43)	49	(21)	46	(20)
Executive function (n=44)	66	(29)	55	(24)
Speed and attention (n=41)	76	(31)	70	(30)

***** The different number of patients is due to internal drop-outs.

Change over time in P-ADL in relation to person's pre- and post-stroke cognitive status from discharge to 6 and 12 months after stroke measured with CIMP-QUEST and MMSE

The persons with an intact pre-stroke cognitive status improved from discharge to 6 and 12 months after stroke (table 6), while those with reduced pre-stroke cognitive dysfunctions did not improve in P-ADL. The persons with intact cognitive status at 12 months after stroke improved from discharge to 12 months, while those with reduced cognitive status 12 months after stroke did not improve in P-ADL (Table 7).

Table 6. Changes over time in P-ADL in relation to person"s pre-stroke cognitive status from discharge to 6 and 12 months measured with MMSE and CIMP-QUEST.

Time	**Changes over time in P-ADL**			
	Intact pre-stroke cognitive status measured with the **CIMP-QUEST** in the acute phase		**Reduced pre-stroke cognitive status** measured with the **CIMP-QUEST** in the acute phase	
	Improved in P-ADL	Not improved in P-ADL	Improved in P-ADL	Not improved in P-ADL
Discharge – 6 months	**X**			**X**
6 – 12 months		**X**		**X**
Discharge – 12 months	**X**			**X**
	Intact cognitive status in the acute phase measured with **MMSE**		**Reduced cognitive status** in the acute phase measured with **MMSE**	
Discharge – 6 months	**X**			**X**
6 – 12 months		**X**		**X**
Discharge – 12 months	**X**			**X**

Table 7. Changes over time in P-ADL in relation to cognitive status from discharge to 12 months in P-ADL in relation to cognitive status after 12 months measured with MMSE and CIMP-QUEST.

Time	**Changes over time in P-ADL**			
	Intact cognitive status measured with the **MMSE** at 12 months		**Reduced cognitive status** measured with the **MMSE** at 12 months	
	Improved in P-ADL	Not improved in P-ADL	Improved in P-ADL	Not improved in P-ADL
Discharge – 12months	**X**			**X**
	Intact cognitive status measured with **Cimp-Quest**at 12 months		**Reduced cognitive status** measured with the **Cimp-Quest** at 12 months	
Discharge – 12 months	**X**			**X**

Changes over time in P-ADL from discharge to 12 months measured with neuropsychological tests

The persons with intact cognition measured with the neuropsychological battery at 12 months improved in P-ADL between discharge and 12 months in all cognitive functions except auditive memory. The persons with impaired cognitive functions did not improve.

Study III

The range of PA values between the raters‟ assessments varied from 53 % to100 % (median 88 %). The PA was in general very good (0.71-1.00) in most of the items (Table 8). In three items there was total agreement, which means that there was no dispersion at all between the raters. PA was moderate (0.53-0.65) in only two items, and these items were *sequencing and judgment/safety* in the task "Paying bills‟".

The results showed that there was no statistically significant occasional disagreement between the raters (RV) about any of the items in the four tasks (Simple Cooking, Using Telephone, Taking Medication or Paying bills), and the RV values were close to zero for all items. The results showed a statistically systematic disagreement (RP) concerning one item, which was judgment/safety in the tasks „‟Paying bills‟". This means that the raters disagreed about that item (Table 8).

The forward and backward translation resulted in some words and phrases needing to be clarified by the professional translator. For example, take the phrase *method of reminding* instead of *cueing system.* This was preferred since there is no good word for cueing in Swedish. Another word that had no good equivalent in Swedish was *mediate* in "executive functions that *mediate* each task", which was translated as "kontrollera" in Swedish (*control)*. Another reservation about the instrument concerned the status of the patients. In the first phase, the occupational therapists assessed patients with mild, moderate and severe stroke. The occupational therapists concluded that the instrument was more appropriate for patients with mild stroke than for those with moderate or severe stroke or patient with aphasia. They assumed that it could sometimes be difficult to test the patients if their motor impairment was too severe or if the patient had aphasia.

Table 2. The Percentage Agreement, occasional disagreement and systematic disagreement as assessed in the Executiv Function Performance Test tasks and items (n=34).

Tasks	Items	Percentage agreement	Occasional disagreement		Systematic disagreement	
Oatmeal preparation			Relative rank variance = RV	Confidence Intervals	Relative position = RP	Confidence intervals
	Initiative	0.88	0.004	-0.005 to 0.015	0.079	-0.211 to 0.052
	Organization	0.94	0.007	-0.014 to 0.028	0.062	-0.060 to 0.185
	Sequencing	0.88	0.002	-0.005 to 0.010	0.000	-0.137 to 0.137
	Judgment/Safety	0.88	0.002	-0.005 to 0.010	0.055	-0.061 to 0.171
	Completion	1.00	0.000	0.000 to 0.000	0.000	0.000 to 0.000
Telephone						
	Initiative	0.94	0.000	0.000 to 0.000	0.003	-0.011 to 0.004
	Organization	0.76	0.009	-0.016 to 0.036	0.010	-0.169 to 0.148
	Sequencing	0.76	0.009	-0.011 to 0.031	0.072	-0.194 to 0.049
	Judgment/Safety	0.82	0.024	-0.038 to 0.087	0.006	-0.175 to 0.189
	Completion	0.94	0.000	0.000 to 0.000	0.000	0.000 to 0.000
Taking medication						
	Initiative	0.94	0.000	0.000 to 0.000	0.058	-0.056 to 0.174
	Organization	0.65	0.029	-0.039 to 0.098	0.051	-0.134 to 0.238
	Sequencing	0.71	0.058	-0.63 to 0.180	0.044	-0.304 to 0.214
	Judgment/Safety	1.00	0.000	0.000 to 0.000	0.000	0.000 to 0.000
	Completion	1.00	0.000	0.000 to 0.000	0.000	0.000 to 0.000
Paying bills						
	Initiative	0.88	0.000	-0.005 to 0.010	0.000	-0.168 to 0.168
	Organization	0.82	0.029	-0.005 to 0.010	0.006	-0.110 to 0.124
	Sequencing	**0.53**	0.058	-0.066 to 0.643	0.076	-0.231 to 0.383
	Judgment/Safety	**0.59**	0.000	-0.076 to 0.262	0.256	**0.032 to 0.480**
	Completion	0.94	0.000	0.000 to 0.000	0.058	-0.174 to 0.056

The bold figures in the column percentage agreement indicate moderate agreement and the bold figures in the confidence Interval of RP indicate statistical significant systematic disagreement in the item judgment/safety in the task „"Paying bills"".

Study IV

In the assessments of the process skills in the AMPS, half of the patients had less than one logit (the cut off), which means that this group needs help from the community, while the other half had over the cut off might live independently. The mean score for the group was 1.05±0.82 logits, and the maximum and minimum were 2.55 and – 0.89. Activities tested in the AMPS are shown in table 9.The most difficult executive dysfunctions in the EFPT for the patients referred to organization, sequencing and judgment and safety. The most difficult task in the test was paying the bills (Table 10).

There were significant correlations between the AMPS process skills and all the four different tasks in the EFPT. (r = 0.54 - 0.60). There was also a significant correlation between AMPS process skills and the total sum of all the tasks in the EFPT (r = 0.61) (Table 11).

Table 9. The Assessment of Motor and Process Scale (AMPS) tasks performed by the participants (n=13).

Tasks
Toast and brewed /made coffee or tea
Sour milk or yoghourt with cereal and beverage
Porridge with milk, beverage and bread with cheese sandwich
Fried egg, toast and beverage
Fried egg, toast and brewed/made coffee or tea
Sandwich on blended bred, brewed/made coffee/tea
Sandwich with meat/cheese and vegetable
Coffee or tea and cake/biscuit served at a table
Wash up the dishes
Vacuum-cleaning, move lightweight furniture
Hand washing, drying, and putting away dishes
Change sheet in a bed placed against a wall, quilt in a duvet cover
Take a shower

Table 10. Distribution of the ratings in the different tasks, in all four tasks and the executive functions in the Executive Function Performance Test (EFPT) and the process skills in the Assessment of the Motor and Process Skills (AMPS) in the study group.

			25-75 th Quartiles		
Tasks	**n**	**Median**		**(Range)**	**Max**
Oatmeal preparation	(n=23)	3	1-7	(0-19)	25
Use telephone	(n=23)	4	0-10	(0-17)	25
Taking medication	(n=23)	1	0-5	(0-23)	25
Bill payment	(n=22)	7	1-14	(0-23)	25
All four tasks	(n=22)	17	2-37	(0-57)	100
Executive Functions in all tasks	(n=22)				
Initiation		0	0-1	(0-6)	20
Organization		4	1-7	(0-13)	20
Sequencing		4	2-8	(0-17)	20
Judgment and safety		5	1-10	(0-18)	20
Completion		1	0-4	(0-8)	20

AMPS	**n**	**Mean**	**SD**	**Range**
	(n=23)	1,05 logit	0,82 logit	-0,89 to 2,55

Table 11. The correlation between the instruments Assessments of Motor and Process Skills (AMPS) and the Executive Function Performance Test (EFPT).

EFPT	**n**	**Spearman's rho**	**P-value**
Simple Cooking	(n=23)	0.54**	P= 0.008
Use telephone	(n=23)	0.60**	P= 0.002
Taking medication	(n=23)	0.56**	P= 0.005
Bill payment	(n=22)	0.57**	P= 0.005
All tasks in EFPT	(n=22)	0.61**	P= 0.002

** Significant at P-value < 0.01

DISCUSSION

General discussions of the findings

That the population in studies I and II had a high frequency of cognitive dysfunctions indicates that it is important to have a relevant instrument in the acute care phase since assessment of P-ADL is not always an adequate method for detecting problems with executive functions (13, 19, 30, 31), and the neuropsychological instruments measure the impairment level and are unable to capture the complexity in many multi-step tasks in activities of daily living (34). Therefore, the EFPT may be an adequate instrument to use at this level since it is not only easy to use but also includes activities that are important for independent living. In EFPT all items to be used in the assessment are in a box, which may seem contradictory to the thinking in occupational therapy, which emphasizes assessing the patient in her or his own context. On the other hand, if the patients get too much help from the contexts the executive dysfunctions probably do not appear. Problems are likely to occur when the patient is faced with an unfamiliar situation, and in this situation it is safe for the patient to be aware of his or her activity limitations and how to use special strategies.

In study II one could find a relationship between cognitive dysfunction and P-ADL after 12 months. This result emphasizes the importance of proper assessment in the acute phase. It is important that occupational therapists have relevant assessments that can detect cognitive dysfunctions, and the EFPT may be a good suggestion. Another valuable aspect is that the goal for the patient in the rehabilitation process must be based on his/her occupational status before stroke (9) since it must be relevant. This means that it is important to involve the next of kin in the rehabilitation process from the beginning as they are the ones that could inform the team about the patient's cognitive ability before stroke onset. As previously shown by the European Stroke Organization (ESO) (75) using extensive systematic literature searching, community-based rehabilitation can improve performance in activities in daily life, and the greatest effects are seen in the older cohort. However, less is known about the optimal components of the therapeutic packages (75). The frequency of cognitive dysfunction is high after stroke, even in the long term, as shown by the present study. As we have demonstrated that patients with different impaired cognitive domains did not improve significantly in P-ADL, there is a need to pinpoint what cognitive problems the patients have and how they could affect an activity, since it could be a question of “hidden cognitive dysfunctions” (76).

If patients" cognitive problems are delineated in the acute phase, it will be easier to give them relevant interventions in order to achieve higher independence or autonomy in everyday life at home. This will most probably improve quality of life as well as reducing costs to society. It has earlier been shown (77) that the costs for mild stroke was lower the first year after stroke due to shorter hospitalisation and less institutionalisation. However, the costs for out-patient care the first year were almost as high for mild stroke as for patients with moderate stroke. This could indicate that problems such as executive dysfunctions were not discovered at the acute care among patients with mild stroke.

In our study we chose more specific neuropsychological instruments than only cognitive screening instruments to measure the cognitive status of the patient. They take more time to administer than screening instruments, which could be a problem in the clinical setting. To delineate the cognitive status of the patient in the clinical setting, a rather new practical bedside cognitive assessment in stroke (78) has now been tested for both validity and reliability. The test is called the Comprehensive Cognitive Neurological Test in Stroke (Coconuts). However, this test did not show good concurrent validity regarding the cognitive functions related to the frontal network, including the executive functions that are important for occupational performance. It might have been more useful to have an instrument to assess the patients in complex instrumental activities.

Earlier studies have shown that patients with mild stroke may have difficulties with executive functions (13, 14). A problem is that there has been a lack of relevant instruments for occupational therapists to assess executive problems in acute care (79). Since patients in acute care who have salient executive dysfunctions may be recruited to a rehabilitation team, there may be a risk that the patients with hidden mild executive dysfunctions will be discharged to their homes without any follow up concerning how they manage in everyday life unless the occupational therapists are provided with a clinically more relevant instrument for assessing their activity limitations beforehand. The screening instrument MMSE is sometimes used to measure the cognitive status of the patient in acute care, but the problem with MMSE is that it fails to detect executive dysfunctions such as abstract thinking, judgment and problem-solving (29, 80).

Our finding that the EFPT is an adequate instrument to use in acute care for patients with mild stroke is valuable, since it involves a dynamic assessment procedure, which is a non-traditional approach to assessments today. It means that the evaluation uses cues and task alterations to identify the person‟s potential for change, and to examine changes in performance. Unlike other instruments, the focus is not only on the outcome of performance but on the process of learning and change, and this provides guidance for intervention (11). The characteristics of dynamic assessment are also the patient‟s awareness of the performance, which is also assessed in the EFPT. The EFPT has several advantages in acute care compared to the AMPS. It is less comprehensive, implying that fewer instructions are needed concerning its administration. It has fewer standardized tasks, which makes it easier to use in acute care. The EFPT has only five standardized tasks compared with the 83 different standardized activities listed in the AMPS. The EFPT needs no special course or rater training and calibration, which makes the test more convenient to use. However, the occupational therapist should be experienced in stroke rehabilitation, and we emphasize that the EFPT must be administered by a senior occupational therapist. The EFPT also has I-ADL tasks suitable for managing the household, such as using the telephone, paying bills and taking medicine, which are not included in the AMPS. Assessing the performance of these tasks is particularly useful if the patient is to be discharged within 1-2 days. The EFPT also includes an intervention part in the assessment, which implies that the instrument may be used to evaluate what guidance is needed to complete the task. This information may be used to educate the next of kin in how to train the patient after discharge from hospital. Finally, the EFPT evaluates if the patient is aware of his or her disability, which is an important factor in the rehabilitation process when it comes to learning new strategies. Those concerned with stroke rehabilitation are paying more and more attention to this aspect.

However, one may question if the tasks in the EFPT are novel enough to detect problems with executive dysfunctions for certain patients with mild stroke. The tasks included in the EFPT may be too easy for some patients who are used to doing them, making it difficult for assessors to detect sublime problems with executive dysfunctions. However, even if the patient is used to doing the task at home, it will be different in another environment (11) . If the assessment with the EFPT shows that there is a risk that the patient will have problems with executive dysfunctions, it is important to follow up the patient with an instrument like the AMPS, as a more comprehensive assessment would be of great value.

Methodological considerations

Our result showed that the cognitive dysfunctions did not have any significant relationship to performance in P-ADL, some explanations need to be found for this discrepancy. The difference could be due to the age of the population, which was older than those in other studies, the exclusion of the group with severe dementia in our study, or to the fact that other studies only used a screening instrument when measuring cognition, or that the studies that found a relationship between P-ADL and cognitive dysfunction applied a different analytical method than ours. These factors may have influenced the results, but the knowledge gained after finishing all four studies, points to another explanation why our and other studies show that cognitive dysfunctions do not have any influence on P-ADL in the acute care phase.

It is suggested that the performance in P-ADL is more automatic and related to the procedural memory (81) than performance in I-ADL. In the literature, it is claimed that a better way to detect executive dysfunctions is by observing the performance of more complex activities such as I-ADL. However, methodologically one may question if the most suitable instrument was used to detect cognitive- or executive dysfunctions. This emphasizes to the importance of evaluating the patients in acute care in more complex activities than P-ADL. However, an even more detailed instrument for measuring P-ADL, such as the Functional Independence Measure (FIM), did not show any relationship with cognitive dysfunction either in acute care (21).

Another important issue is that one may question the early assessment of cognitive and executive functions in acute care since executive dysfunction also may depend on depression or crisis after stroke. However, regardless of the cause of the executive dysfunction, the patient and his/her family need support to understand the difficulties he/she is likely to have to cope with in everyday life. If the patient is found to have hidden cognitive dysfunctions in the acute care phase, it is important to catch these problems as early as possible. Further support to claim that hidden cognitive problems are best detected in novel instrumental activities may be found in Toglia (11), who emphasized that independence in the community requires the ability to deal with unfamiliar, novel and unpredictable situations.

One issue is how valid the reports from the next of kin were when they used CIMP-QUEST to answer questions about how the patients performed activities in their homes with respect to cognitive and executive functions. However, in a study (82) where proxy and

patient agreement was assessed regarding self-care, I-ADL, memory, emotions and communication, the agreement was found to be acceptable for observable physical behaviours. Although there was less agreement between the assessments of memory and emotion, the bias was not thought to be clinically meaningful. In CIMP-QUEST, the next of kin do not assess cognitive function in an abstract way, without relating the cognitive behaviour to activities in everyday life. This kind of proxy assessment is therefore becoming more physical-like and may also be more valid than more the assessment of abstract cognitive behaviours (82).

No doubt a power calculation of the sample size of the population in studies I and II would have resulted in a higher probability that the results had a true effect, this is a limit of our study. In study II, we did many significant tests in a small sample, one may wonder, on the one hand, whether there was a risk of committing a mass significance or type- II error.

On the other hand, the medians and percentiles showed that the results were reasonable, since the medians had changed more in the group who had intact cognitive functions than in the group whose cognitive functions were impaired.

In study III the non parametrical rank-transformable method was used. The analytical method Kappa (72) is the most common one for evaluating inter-rater agreement. The advantage of using kappa is that it takes chance into account (83). The reason why we could not use that method in study III to analyse agreements between the raters was that the method results in a prevalence effect (84, 85) which means that the values differ very much from the percentage agreement. This may happen if the sample is small or if the values are asymmetric (83). On the other hand, if the prevalence effect occurs, one can, as we did, analyse the inter-rater reliability using percentage agreement (72) and the non-parametric rank-transformable method(73, 74), which can identify if there is a statistically systematic and occasional disagreement between the raters. In study III there was a significant systematic disagreement on safety/judgement in the task “Bill payment“. This may depend on the fact that safety could be difficult to assess because it is more abstract than a physical task. This was also seen in another study (83). An additional aspect is that the task “Bill Payment” is the most complex of the four tasks in EFPT. A third explanation could be that the manual was not explicit enough about this item. When the contingency table was analysed, it was found that one of the raters assessed more severely than the other. One aspect of the raters‟ assessment which could have

been done better was discussing any difficulties that arose when the raters tested the instrument in several patients besides those related to the language used in the manual. Maybe this type of discussion would have reduced the difference between the raters‟ assessments of some items. Further explanation for the good result could be that the raters had learnt the idiosyncratic patterns of the other rater so that their assessments became similar (86). To prevent this limitation, it could have been better to have several other raters in our study instead of using the same pair the whole time. The sample in the evaluation of the inter-rater reliability was small, which makes it difficult to generalize. On the other hand, another study (48), which also evaluated the inter-rater reliability in EFPT, but using another method, showed the same result with the similar population.

Regarding the translation process, the most common method is the forward and backward translation (FB) as performed in this study (71, 87). The FB is important to achieve good quality (88). Other studies recommend more than one translator both in the forward and backward translation process, but that is more costly and time-consuming. Having more translators is more relevant when the instrument is more comprehensive with more items than our instrument has. The EFPT has only four activities with five items each. Since an FB translation does not automatically lead to conceptual, semantic and culture equivalence, two different groups experienced in the use of EFPT evaluated the translated version to ensure that it was conceptually, semantically and culturally equivalent to the original text. The experience of the members of these groups was very important not only in reaching a comprehensive understanding of the instrument, but also in facilitating the evaluation of the psychometric testing in which the occupational therapist participated. The discussions with more than one group, as occurred in this study, are rather similar to a method called dual-panel approach (89). The dual-panel approach consists of a group of bilingual people native to the target language discussing items together with a representative of the developers of the adapted instrument, which was also done in our groups. This is followed by a review of the first translation by a second panel consisting of people who can ensure acceptability of wording and ease of completion, including both the conceptual, semantic and cultural relevance (71, 88, 90). The second expert group was the group which discussed the conceptual, semantic and cultural relevance in the manual of the EFPT. Another translation aspect concerned some instructions for the task “Paying bills” in which the meaning was not totally clear. A group discussion with the second expert group resulted in no solution to this problem. Instead, the

first author (MC) had a further discussion with the editor- in-chief of the original version to understand the intention of the instruction. The first author (MC) was then able to discuss the intention with the group and clarify the instructions.

In study IV the same person performed the assessments that must be considered as a strength which will increase the reliability of the evaluations. On the other hand, it is more realistic to have several raters using the instruments in hospital, and in that case it is important to evaluate if there is any systematic disagreement between the raters (91). It is important when evaluating concurrent validity that the assessments should be performed within a short time, otherwise the patients‟ status may have changed and may cause a bias. In the present study, 78 % (n=18) of the patients were assessed within two days, which was good since the patients might have been too tired in the acute phase to be assessed with two instruments in one day only.

One may question why the correlation between the EFPT and the AMPS was only moderate (92). However, the purpose of the two instruments differs even if they both evaluate executive performance skills. One of the biggest differences between the instruments is that AMPS focuses on the quality of occupational performance and the EFPT focuses on the intervention part, in which the patient is supported with levels of guidance to manage the tasks. These differences may explain why the correlation was moderate.

The research presented is based on a limited number of patients and future research should be performed in larger samples.

CONCLUSION

Neither the presence of pre-stroke dementia nor the patient‟s cognitive status after stroke onset showed any impact on P-ADL or independence in the acute phase after stroke. After 12 months, however, a relation was shown between P-ADL and cognitive and executive dysfunctions. These findings may indicate that the recovery of P-ADL in elderly patients after stroke is influenced by more factors than cognition or that assessment of P-ADL does not always detect cognitive and executive dysfunctions. The results demonstrate that it is important to use more complex activities in assessing the patient‟s activity status since executive dysfunctions are more easily detected in tests with instrumental activities in daily life. Since there is a risk in the acute stroke care that some patients with mild stroke will be discharged without any rehabilitation, and occupational therapists have up till now lacked a relevant instrument for detecting problems with executive skills in acute stroke care, it is suggested that the EFPT is a suitable instrument for use in these patients, since it has been shown that the concurrent validity was highly significant and the interrater reliability was very good.

Swedish Summary

Bakgrund: Stroke är en av de största folksjukdomarna i Sverige. Årligen insjuknar ungefär 30 000 personer och 80 % är äldre personer över 65 år. Medianåldern för insjuknandet i stroke är 75 år. Den totala vårdkostnaden per år är ungefär 14 billioner svenska kronor. Studier av stroke har mest fokuserat på fysiska nedsättningar och överlevnad, men de sista 10 åren har mer forskning inriktats på kognitiva funktionsnedsättningar och dess konsekvenser på utförandet av aktiviteter i det dagliga livet, vilket innefattar personlig vård, aktiviteter för att klara av att sköta sitt hushåll, fritidsaktiviteter och arbete. Studier har visat att det är vanligt med kognitiva och exekutiva nedsättningar efter stroke, men det finns motsägande bevis hur kognitiva problem påvekar aktiviteter i det dagliga livet. Arbetsterapi som ämne fokuserar på bedömning och träning av aktiviteter i det dagliga livet, därför är det viktigt att undersöka om det finns någon relation mellan kognitiva - och exekutiva nedsättningar och personlig vård i det akuta skedet och efter ett år. Det finns en brist på bedömningsinstrument att använda för arbetsterapeuter i det akuta skedet för patienter med mild stroke. Det finns därför en risk att patienter med ”osynliga problem” såsom milda kognitiva och exekutiva nedsättningar skrivs ut till hemmet utan någon rehabilitering. Därför är det av största betydelse att arbetsterapeuter har ett lämpligt bedömningsinstrument för att fångar dessa problem.

Syftet med avhandlingen var att undersöka aktivitetsutförande i personlig vård i relation till kognitiv och exekutiv nedsättning hos äldre personer med mild stroke i det akuta skedet och efter 12 månader, och att utvärdera instrumentet ” Executive Function Performance Test ” (EFPT) hos patienter med mild stroke.

Metod: Sextio äldre patienter som fått diagnosen stroke ingick i den första studien. De remitterades till en avdelning för geriatrisk rehabilitering. Bedömningarna gjordes när de skrevs in och när de skrev ut från avdelningen. Medelåldern för studiegruppen var 77 år. I den andra studien ingick 45 av de 60 patienter som inkluderades i den första studien. Dessa bedömdes vid utskrivning från avdelningen, och vid 6 och 12 månader efter stroke insjuknandet. Frågeformuläret Cognitive Impairment Questionnair (CIMP-QUEST) användes för att intervjua en nära anhörig om patientens kognitiva status. Patientens utförande av personlig vård bedömdes med Barthel Index (BI). Mini Mental State Examination (MMSE) och neuropsykologiska test användes för att bedöma patientens kognitiva nedsättningar.

National Institute of Stroke Scale (NIHSS) användes för att mäta patienternas neurologiska nedsättningar. I den tredje studien var det fyra arbetsterapeuter, två par, som gjorde 34 bedömningar på patienter med mild stroke. Bedömningarna utfördes på en strokeenhet med instrumentet EFPT för att utvärdera tillförlitligheten mellan bedömarna (interbedömarreliabilitet) d v s om bedömarna gjorde likadana bedömningar av samma patient. I fjärde studien var det en arbetsterapeut som gjorde bedömningar på 23 patienter från en strokeenhet med EFPT och Assessment of Motor and Process Skills (AMPS) för att utvärdera samstämmigheten mellan EFPT och AMPS.

Resultat: I den första studien var det varken demens före insjuknandet eller kognitivt status efter insjuknandet i stroke som påverkade utförandet i personlig vård vid inskrivningen eller vid utskrivningen i det akuta skedet. I den andra studien var det ingen signifikant förbättring i personlig vård efter 6 eller 12 månader för de personerna med demens före insjuknandet eller kognitivt nedsättning efter insjuknandet i stroke. Däremot förbättrades patienterna med intakta kognitiva funktioner signifikant i personlig vård. Den tredje studien visade att samstämmigheten mellan de bedömningarna som de två arbetsterapeutparen hade gjort var mycket bra (88 %) och att EFPT var tillförlitligt. Bedömningarna skiljde sig inte slumpmässigt från varandra. I tre av 20 moment var det total samstämmighet, vilket betyder att det inte fanns någon oenighet mellan bedömarna. I endast ett av 20 moment fanns det en systematisk skillnad. I den fjärde studien hade korrelationen mellan EFPT och AMPS hög signifikant och den samtida validiteten var moderat, vilket visar att den samtida validiteten var rimlig mellan de två instrumenten.

Slutsats: Varken demens före insjuknandet eller kognitiv nedsättning efter insjuknandet i stroke påverkade utförandet i personlig vård vid in- eller utskrivningen i det akuta skedet. Men efter 6 och 12 månader var det en signifikant förbättring av utförandet i personlig vård för de personerna som inte hade demens före insjuknandet och eller inte hade kognitiva eller exekutiva nedsättningar efter insjuknandet i stroke. De med intakta kognitiva och exekutiva funktioner hade således förbättrats alltså. Dessa resultat visar att återhämtningen i utförandet i personlig vård hos äldre efter stroke påverkades av fler faktorer än kognition eller av att bedömningen i personlig vård inte alltid visar på kognitiva eller exekutiva problem. Resultaten visar att det är viktigt att använda aktiviteter som är mer komplexa än de i personlig vård när patienterna bedöms i det akuta skedet, eftersom exekutiva färdigheter

upptäcks lättare i mer komplexa aktiviteter än de i personlig vård. Eftersom det finns en risk att patienter med mild stroke skrivs ut från det akuta skedet utan någon rehabilitering och att arbetsterapeuter nu saknar ett relevant instrument att påvisa problem med exekutiva färdigheter i det akuta skedet, föreslås utifrån avhandlingens resultat att EFPT är ett passande bedömningsinstrument att använda för denna patientgrupp.

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