Stroke rehabilitation:

A randomized controlled study in the home setting; Functioning and costs.

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ABSTRACT

Aim: The purpose of the thesis was to describe and evaluate different aspects of rehabilitation after discharge for persons of working age after stroke. Aims were to compare an approach of support, information and training in the home setting with ordinary outpatient rehabilitation at the clinic and to describe the costs and factors influencing the costs.

Method: Fifty-eight persons, median age 53 years (27-64), with a first occurrence of stroke, participated in a randomized controlled study following ordinary in-patient rehabilitation. They received 9 hours of training per week for 3 weeks after discharge either at home (home group, N=29) or at the day clinic (day clinic group, N=29). Blinded evaluations were made at discharge, 3 weeks, 3 months and 1 year post discharge. For outcome, the assessments targeted the different components of the ICF. The main outcome was activity, assessed with the Assessment of Motor and Process Skill (AMPS). Burden of care for the next-of-kin was investigated in the groups. Societal costs for having a stroke were estimated as well as the cost of the two interventions. Rasch analysis was performed on the European Brain Injury Questionnaire (EBIQ) to assess its reliability and validity for outcome evaluation.

Result: In the post acute phase most improvement occurred in activity. There seemed to be an earlier improvement on some measures for the home group. The costs of the home group were less than half of the costs of the day clinic group. The caregiver burden was quite high in this study on relatively mild strokes indicating that other aspects than neurological influence the burden. The process skill and presence of aphasia were found to be significantly affecting the length of stay and thereby the cost. The instrument EBIQ was found to be valid and reliable for evaluation.

Conclusion: Rehabilitation in the home setting seems to reduce burden of care and costs. Both rehabilitation programs could be recommended; however, further studies are needed to define patients who may specifically benefit from the home rehabilitation program. Needs may differ among younger and older persons which may explain the differences found in resource allocation.

Key words: rehabilitation, ADL, cost, home, caregiver, outcome, adaptation, occupational therapy

LIST OF ORIGINAL PAPERS

This thesis is based on the following four papers, which will be referred to in the text by Roman numeral.

I   A Björkdahl, Å Lundgren Nilsson, K Stibrant Sunnerhagen
The structural properties of the European Brain Injury Questionnaire**.**
J Stroke Cer Disease 2004;13,122-128.

II   A Björkdahl, Å Lundgren Nilsson, G Grimby, K Sunnerhagen
Does a short period of home rehabilitation facilitate functioning after stroke?
A randomised controlled trial.
Clin Rehab 2006;20:1038-1049.

III   A Björkdahl, Å Lundgren Nilsson, K Stibrant Sunnerhagen
Can rehabilitation in the home setting reduce the burden of care for the next of kin of stroke victims?
J Rehab Med 2007;39:27-32

IV   A Björkdahl, K Stibrant Sunnerhagen
Process skill rather than motor skill seems to be a predictor of costs for a stroke patient in working age; a longitudinal study with a 1 year follow up post discharge.
Submitted

CONTENTS

INTRODUCTION

Stroke and several other chronic diseases appear often suddenly. After diagnosis the medical service provides treatment and rehabilitation. However, for the individual it is a life catastrophe to which it is important to adapt well. The individual needs to be aware of what has changed to be able to regain as much as possible in training. To some extent some things will not be the way they were before, and the individual must thus cope with the limitations and adapt to the new life situation. To adapt well, rehabilitation must focus on the right things at the right time in the right context and involve persons of importance in the environment. This is not easy for the individual or for the rehabilitation providers. To provide the best possible rehabilitation the field needs to examine different approaches for treatment and interventions and to use valid and reliable instruments for evaluation. Evaluation is needed so that the persons are able to see whether the intervention has the desired effect and so that the field of rehabilitation is able to demonstrate evidence.

The ICF

The International Classification of Functioning, Disability and Health (ICF) provides a frame of reference that is helpful for choosing the proper measures for an intervention when the outcome variable is known. In new and more complex interventions it may be advisable to use several outcome variables and to evaluate different aspects such as the different components in the ICF.

ICF was published in 2001 by WHO as the successor to ICIDH describing health and health-related conditions (WHO 2001). The development of the ICF was a conceptual shift from "a consequence of disease classification" to "a components of health classification". The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states. It organises information in two parts where part one include functioning and disability and part two contextual factors. The ICF encompasses functioning as a human experience that can be conceptualised and classified from different perspectives: the perspective of the body (body function and structure) and the perspective of the individual and the society (classification of activities and participation) (fig 1). The ICF model presents functioning and disability as a consequence of an interaction between a person's physical or mental condition and his or her social and physical environment. One umbrella term is functioning, which covers body function and activity as well as participation. Another is disability, which is used to include impairment (of body function and body structure), activity limitation and participation restriction. Body function includes physical as well as psychological functions on an organ level. Activity is defined as the execution of a task or an action by an individual. It can refer either to an individual's capacity to carry out a task or to that person's actual performance of the task. Activity limitations are difficulties that an individual may have in executing activities. To render such a model meaningful in

rehabilitation, however, the environment too should be described, and this is now possible with the ICF. Participation is defined as involvement in a life situation and participation restriction as problems an individual may experience while involved in life situations.
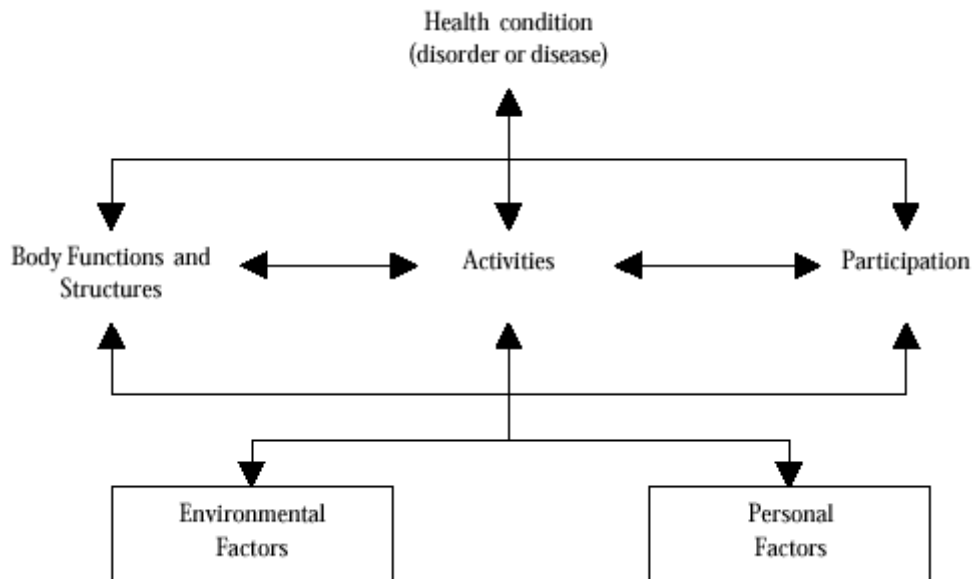

Figure 1. The ICF classification.

Contextual factors represent the complete background of an individual's life and living. They include two components: environmental factors and personal factors, which may have an impact on an individual with a health condition and that individual's health and health-related states. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. The environmental factors are organized according to individual (the immediate environment of the individual, i.e. home, workplace, school etc) and societal (formal and informal social structures, services and systems in the community that have an impact on the individual). Personal factors are the particular background of an individual's life and living and comprise features that are not part of a health condition or health states such as gender, age, lifestyle, coping styles etc. The personal factors are not classified in the ICF but are included in the figure above to show their contribution, which may have an impact on the outcome of various interventions.

Rehabilitation

Rehabilitation is a set of philosophies, treatments and therapies that when combined with natural recovery, is intended to enhance patients' potential for participating in meaningful life experiences (Stineman 2001). It can be seen as a learning process, aimed at the acquisition of novel skills or the reacquisition of old skills with its main goal to regain optimal functional independence (Hochstenbach 2000). The World Health Organization defines rehabilitation as the combined and co-ordinated use of medical, social and educational measures for training or retraining the individual to the highest possible functional ability (WHO 2001). The WHO´s definition of rehabilitation connects clearly to the ICF model. Rehabilitation medicine within the health care setting is the area where different professions meet and work in teams together with the patient to reach a common goal. Rehabilitation medicine ultimately aims at restoring behaviours and perceptions (such as independence, balance, continence and fatigue) through behaviours (such as exercise, teaching, counselling and functional assessment) (Tesio 2003). Roth et al. (Roth et al. 1998) find that there is a relation between impairment and disability but suggest that rehabilitation has an independent role in improving functioning beyond that explained by recovery alone. Rehabilitation relies on both remediational interventions designed to reduce for example neurological deficit and on teaching compensatory techniques to enhance functional independence in the presence of impairment to give possibilities for participation and quality of life. This is also reflected in the research within rehabilitation medicine.

Occupational therapy

In rehabilitation the occupational therapist is usually one of the different professions that contribute their perspective and knowledge to reach the common goal of the rehabilitation. Occupational therapists build their competence on frames of references from occupational therapy and related fields, such as psychology, medicine etc. A central concept in occupational therapy is occupation (activity). Occupation means what people do and comprises all situations in which the individual takes an active part (Meyer 1922). Occupation is in many aspects similar to activity in the ICF. In occupational therapy rehabilitation is seen as a process of facilitating a gradual return to previous daily living routines. "During rehabilitation, the individual seeks to maintain or re-establish habits and patterns of daily occupation that have gradually developed over many years" (Hasselkus 2002). In occupational therapy another central concept is adaptation, which can be described as the fit between the individual's capacities and the demands for performance. Adaptation includes both adaptation in the way of learning and using strategies in order to compensate for limitations and coping by using purposeful coping strategies. In practice we often observe that clients with similar deficits or the same disability have remarkably different results of therapy. Some appear to respond quite well, adapt readily to changes in their life and experience favourable outcomes. Others have a more difficult time. Clearly,

factors other than the nature the severity of the condition, or even the type of intervention, account for these differences (Christiansen 1991; Cohen and Lazarus 1979). An important theoretical model in occupational therapy is the Model of Human Occupation, MoHo (Kielhofner 1985). In the model, occupation is seen as a dynamic interaction between the individual, the task and the environment. There are four main factors influencing occupational behaviour: volition, habituation, mind-brain-body system and the environment. Volition is a collection of thoughts and feelings pertaining to one's abilities and effectiveness, enjoyment and satisfaction and what is important and meaningful. Habituation consists of habits and roles. The mind-brain-body performance system is conceptualised as the capacities underlying motor, process and communication/interaction skills. With this view of a dynamic interaction there are several aspects to control for when offering an intervention.

Further development and clarifications of concepts in MoHo were done when designing the conceptual model of the AMPS, Assessment of Motor and Process Skills (Fisher 1995, 2003). It was then asserted that functional behaviour (occupational performance) is a complex set of interactions between the person and his or her environment. Skills are always jointly determined by the person, the task and the precise environment in which the actions take place. Therefore, the development of the AMPS instrument is based on the premise that accurate determination of a person's ability to perform daily life tasks is most directly assessed through the evaluation of his or her skills (practiced abilities) observed in the context of his or her dynamic interaction with the environment during the performance of a specified task. Occupational performance is viewed as a meaningful sequence of actions in which the person enacts and completes a specified task that is relevant to his or her culture and daily life roles.

Relationship between the conceptual model of the AMPS and the ICF

The conceptual model of the AMPS is a frame of reference for the occupational therapist developed from the MoHo as an underlying concept guiding the occupational therapist in the work with a patient and the ICF framework, which can serve as a tool to provide a unified and standard language and framework for the description of health and health-related states, are in the main similar but differ in some aspects. It may be important to look at the differences so that the ICF can be employed consistently even when the user has a background as an occupational therapist. Both models view body function or mind-brain-body as a factor influencing activity or occupational performance. Both also regard the environment and personal factors (the concepts of volition and habituation in the AMPS conceptual model) as important factors in functioning. However, they are not completely comparable as the activity concept in ICF is broader than the concept of occupational performance in the AMPS model (fig 2).
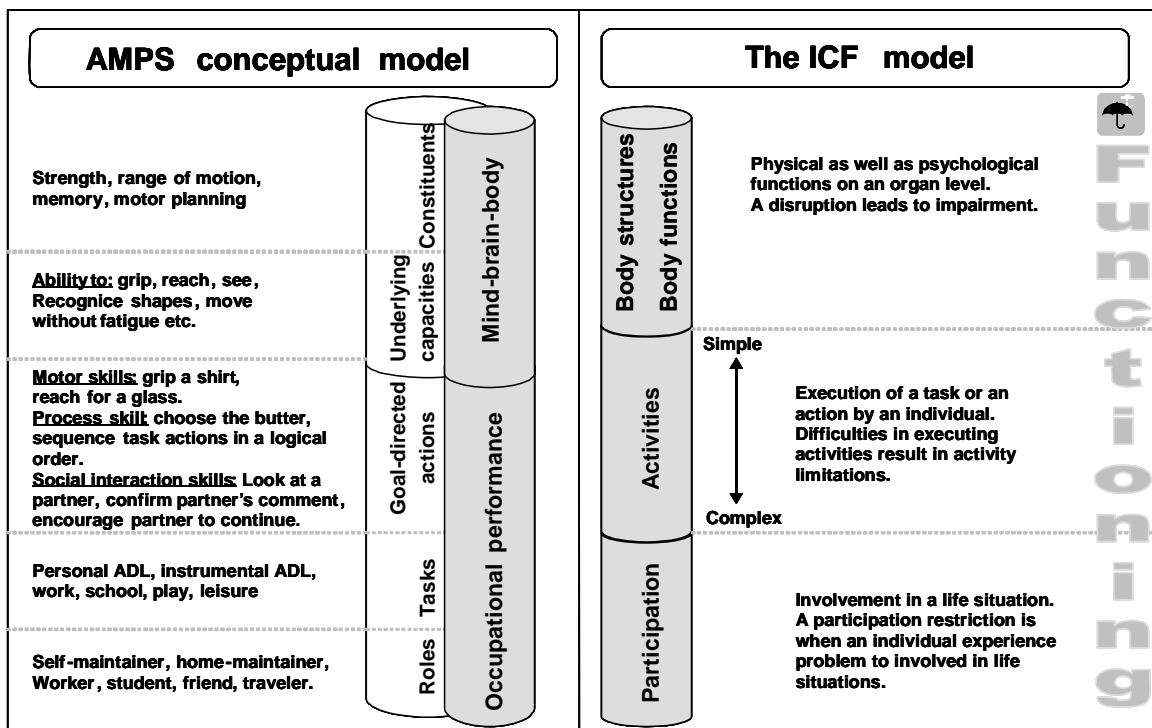
AMPS conceptual model

Strength, range of motion, memory, motor planning

Ability to: grip, reach, see, Recognice shapes, move without fatigue etc.

Motor skills: grip a shirt, reach for a glass.
Process skill: choose the butter, sequence task actions in a logical order.
Social interaction skills: Look at a partner, confirm partner's comment, encourage partner to continue.

Personal ADL, instrumental ADL, work, school, play, leisure

Self-maintainer, home-maintainer, Worker, student, friend, traveler.

Underlying capacities | Constituents | Mind-brain-body

Goal-directed actions

Roles | Tasks

Occupational performance

The ICF model

Body structures | Body functions

Physical as well as psychological functions on an organ level. A disruption leads to impairment.

Activities

Simple

Execution of a task or an action by an individual. Difficulties in executing activities result in activity limitations.

Complex

Participation

Involvement in a life situation. A participation restriction is when an individual experience problem to involved in life situations.

Functioning

Figure 2. Relationship between the ICF (body functions, activities and participation) and the AMPS conceptual model (the mind-brain-body and occupational performance).

In the ICF, activity is used to classify both an individual's capacity and that person's actual performance while in the conceptual model of the AMPS, underlying capacities such as ability to grip and walk are seen as mind-brain-body (to be compared with body function and body structures) and a meaningful sequence of goal directed actions is viewed as occupational performance (activity). In the ICF participation is defined as an involvement in a life situation and in the AMPS conceptual model it can be viewed as being related to role competence and satisfaction. The figure above, taken from the AMPS manual (Fisher 2003) (fig 2), shows how these concepts are related to each other. In both the ICF and the AMPS conceptual model personal and environmental factors are not viewed separately but as having an impact on functioning (ICF) or occupational performance (AMPS conceptual model).

Adaptation

The dictionary definition of adaptation is a change or adjustment that a person makes in his or her response approach when that person encounters an occupational challenge, which after a stroke could be transporting oneself to another place, do shopping, planning and preparing a meal etc. The person tries in the best way to master the challenges. Most disciplines addressing adaptation see it as belonging to the human evolution and a change as described above is usually seen as the relation between stress and coping. Cohen and Lazarus (Cohen and Lazarus 1979) view the terms adaptation and coping in a hierarchical way, where adaptation is the superior term. Coping comprises specific reactions to specific situations while adaptation is a broader term that stands for an individual's ability to adapt to demands (Christiansen 1991). A brain injury is a traumatic and stressful event and can be connected to coping. However, in the light of a longer perspective after an injury, the individual encounters continuous challenges as a result of a change in ability that must constantly be addressed in a new way with the new conditions, and this could be an adaptation since the life situation is altered. Nelson (Nelson 1996) writes that occupational adaptation as a therapeutic goal will be for the therapist to help the person to set up a situation in which performance will lead to self-change. The stroke not only affects the stroke victim but all who are closely connected to the situation and the need for adaptation involves all of them (Hasselkus 2002). Self-change can both be practical, such as learning strategies for dressing, or a change in awareness or how to think and feel about the situation.

Outcome

To ensure the best possible rehabilitation there is a need to reflect about what kind of outcome should be addressed and how to evaluate the result. Although outcomes in rehabilitation are best measured at the points where the interventions primarily act, interventions in one area may invariably affect outcomes in others (Stineman 2001). Outcomes may be specified at a variety of levels, including disease, impairment, activity or participation (Whyte 2003). In rehabilitation, one is typically most interested in relatively macro outcomes such as activity and participation because of their real-world significance. However, outcomes are dependent on many factors besides the specific treatment and may be insensitive to even relatively large treatment effects (Whyte 1997). The same treatment may be judged effective or ineffective depending on the outcome measures chosen (Whyte 1997). Similar impairments can yield different functional difficulties and identical difficulties may be caused by different impairments because of varying contexts (Stineman 2001). In the early stages of treatment research, it is generally advisable to assess multiple outcomes because the precise effects of the treatment may not be fully understood. From a service perspective two main outcomes appear important: what we may wish patients to be doing (achievement of valued social roles) and how we wish them to feel (psychosocial adjustment) (Williams 1999).

Functional outcome is measured by evaluating the patients' performance on any of numerous functional status measures (Fisher 2003; Katz et al. 1963; Keith et al. 1987; Mahoney and Barthel 1965). Tools used to measure outcome must be reliable, valid and discriminative. Examining the discriminative ability of a measure is important for ensuring that a chosen outcome measure is able to differentiate within the patient group and to identify meaningful differences in patients' abilities (Brock et al. 2002). The quality of an outcome will depend on both the concrete change in status and the subjective experience of that status change (Stineman 2001).

Operationalizing and then measuring variables are two of the necessary first steps in the empirical research process. Statistical analysis as a tool for investigating relations among the measures then follows. Thus, interpretations of analyses can only be as good as the quality of the measures (Bond and Fox 2001). In real life we often observe phenomena related to individual objects or persons. These phenomena appear to us as discrete: they either happen or they do not. Measurement begins by counting these discrete observations, but in order to have "quantity" we need to have continuous linear measures. A measurement model that can be used to develop interval-scaled measures from ordinal scores is the Rasch model (Rasch 1960).

Rasch models

Rasch analysis is an approach to the measure of human performance, attitudes and perceptions. It is named after its inventor, the Danish mathematician George Rasch who published his theory in 1960 as a psychometric tool for use in the social science and education. Today the Rasch analysis is quite often used in the area of rehabilitation as activity and participation is the focus of evaluation in rehabilitation and the outcome in these areas is complex: not a single variable such as blood pressure, but perceptions or complex situations. In addition, most of the instruments use ordinal scales. Rasch models are probabilistic mathematical models. Under the Rasch model expectations, a person with higher ability always has a higher probability of endorsement or success in any item than a person with lower ability. Likewise, a more difficult item always has a lower probability of endorsement or success than a less difficult item, regardless of a person's ability (Rasch 1960).

Rasch models require unidimensionality and result in additivity (Brogden 1977; Karabatsos 2001; Perline et al. 1979). Unidimensionality means that a single construct is being measured. Additivity refers to the properties of the measurement units, which are the same size (i.e., interval) over the entire continuum if the data fit the model (Fischer and Molenaar 1995; Perline et al. 1979). These units are called logits (logarithm of odds units) and are a linear function of the probability of obtaining a certain score or rating for a person of a given ability. These interval measures may be used in subsequent parametric statistical analyses that assume an interval level scale (Rasch 1960).

Items and persons are placed on a common scale, items according to their difficulty or endorsability and persons according to their ability or level of symptomatology. The probability of a person endorsing an item is based on a person's level of the underlying concept and not the person's relationship with others in the sample (Rasch 1960).

In addition to producing interval-level measures the Rasch model also provides techniques for evaluating the psychometric characteristic and the quality of the measures produced (Bode et al. 2000). In study I the focus is on two criteria of quality, reliability and validity. Reliability concerns issues of precision and how consistent a score is obtained. It is typically evaluated in terms of an instrument's internal consistency or stability of its scores. The internal consistency tells you how well a set of items cohere to each other. Cronbach´s alpha is often used for this purpose. High stability of the scores is obtained when there is a consistency of scores across occasions or raters. The stability is typically evaluated by correlating scores over time. As correlation analyses tend to be sample dependent, the Rasch model instead evaluates the reliability of a measure in terms of separation. Separation is a function of the spread in the measures and the error in estimating them. High separation indicates that measures vary because people truly possess or tasks truly characterize different amounts of the attribute (taking into account the measurement error). The Rasch analysis also produces an estimate of separation reliability that is interpreted in a way similar to Cronbach's alpha (Bode et al. 2000).

Validity concerns the meaning of scores derived from an instrument. Construct validity emerges if sufficient evidence exist that the instrument measures its intended construct. The construct validity is determined by examining the hierarchy of the tasks as well as by evaluating the "fit" of individual tasks to the latent construct. The Rasch analysis also assesses the targeting (the extent to which items are of appropriate difficulty for the sample). An even spread of items indicates that most regions of the variable are defined or tested. Good tests usually have the items targeted (lined up) with the persons (Linacre 2002).

Stroke in younger persons

Stroke is one of the leading causes of disability in the Western world. In Sweden, with 9 million inhabitants, the incidence is about 30 000 per year, with around 100 000 persons living in society with the consequences of a prior stroke. The incidence in persons younger than 65 years is around 10 000 per year and stroke incidence increased in the age group of 30 to 65 years between 1998 and 2000 (Medin et al. 2004). Despite modern medical treatment, new drugs, multidisciplinary rehabilitation and stroke units, still about half of stroke survivors are discharged with disabling sequelae often remaining for the rest of their lives (Andersen et al. 2002). There will be considerable consequences for the health care system and other support systems with an increasing incidence of stroke among younger persons of working age. In the age group studied by Medin et al.(Medin et al. 2004) 65 % were male and 35 % female. The distribution of different subtypes of stroke was similar

among men and women. Cerebral infarction (CI) accounted for the majority of cases (75 %) and the intracerbral haemorrhage (ICH) for around 20 % of the cases. The percentage of haemorrhage is higher in this younger age group than in the total population (CI 85 %, ICH 10 %) (Riks-stroke 2002).

There are limitations in many stroke-related studies since they have largely consisted of people over the age of 65 years and there is reason to believe that there may be differences in younger and older age groups. Using mid-1980's data applied to present populations, it can be estimated that 25 % of all people with stroke living in community housing will be under the age of 65 (Kersten et al. 2002), the age of retirement in Sweden. Many of these younger people survive their stroke for longer periods.

The physical, cognitive, emotional and behavioural consequences have an important impact on everyday life, family functioning and social interactions. Stroke survivors must cope with residual limitations in function and activity as well as in participation (Tennant et al. 1997). As a consequence of their age, younger people with stroke have to deal with issues such as loss of employment and difficulties in family activities such as raising children (Kersten et al. 2002). The main functional limitation in the young survivors of ischemic stroke occurs in work activity, since most patients are independent in personal activities of daily living but many of them do not return to work (Varona et al. 2004; Vestling et al. 2003). There is a wide range in reported results of return to work (10 % - 84 %) (Saeki 2000; Wozniak and Kittner 2002). Kersten et al.(Kersten et al. 2002) reported that 64 % of the young stroke patients in their sample had difficulties in their sex life. In their study of unmet needs the most frequently unmet need was found to be personalized information about strokes. The younger age group also reported statistically significantly more unmet needs for intellectual fulfilment, a holiday and family support than responders in the older age group. As the younger stroke patient seems to have different or additional needs over those of the older aged patient, there is a need to study the age groups separately.

Organisation of rehabilitation for patients after stroke

Rehabilitation medicine has largely developed as a hospital-based speciality. This is understandable given the need for post-acute rehabilitation after such a common event as stroke. In addition, when there are relatively few specialists in the field there is an understandable tendency for such specialists to work from a single hospital (Barnes and Radermacher 2001). There is evidence today that acute stroke patients should be offered organised inpatient (stroke unit) care, which is typically provided by a coordinated multidisciplinary team operating within a discrete stroke ward that can offer a substantial period of rehabilitation if required (Stroke Unit Trialists´ Collaboration 2002). In the Western world stroke consumes about 5 % of the health service resources within national health services. Much of this cost is attributable to the care of disabled stroke patients in

hospital (Early Supported Discharge Trialists 2005). Services for reducing the duration of hospital care have now been developed that offer patients in hospital an early discharge with rehabilitation at home. There is evidence that Early Supported Discharge (ESD) services provided for a selected group of older stroke patients can reduce long term dependency and admission to institutional care as well as reduce the length of hospital stays (Early Supported Discharge Trialists 2005).

There are many models of rehabilitation in the community. These range from community-based multidisciplinary teams to individual therapists or nurses working either directly in the community or on an outreach basis from a hospital unit. The multidisciplinary teams appear to be two main types, one with the aim of early discharge and the other type with an aim to provide rehabilitation in the home as an alternative to hospital-based rehabilitation (Barnes and Radermacher 2001). The second type, "hospital at home", is defined as an alternative service to acute hospital in-patient care that can not be supported as a cheaper alternative to stroke unit or other in-patient care (Shepperd and Iliffe 2000). The out-patient rehabilitation provided for stroke patients in the community are those provided by physiotherapy, occupational therapy or multidisciplinary staff working with patients primarily to improve task-orientated behaviour (e.g. walking, dressing) and hence increase activity and participation. These kinds of targeted services for stroke patients living at home appear to improve independence in personal activities of daily living (Outpatient Service Trialists 2005).

In Sweden, stroke patients of working age are often referred to rehabilitation in a rehabilitation clinic. Patients who receive a referral for rehabilitation are usually those predicted to return to the home but who need more time for in-patient rehabilitation than can be given at the stroke unit. These rehabilitation units often work in close collaboration with the primary stroke unit. When patients at the rehabilitation clinic are ready to leave the hospital, most are offered additional training at a day clinic.

Discharge from hospital to the home can be a critical stage in the rehabilitation of patients with stroke due to the difficulty of transferring new skills achieved in hospital to the home environment (Gilbertson et al. 2000). A study by Martin et al (Martin et al. 2002) confirms that support after discharge from hospital following a stroke can be inadequate. Stroke patients and their families may experience a number of practical difficulties due to a lack of information about the condition and its consequences and a poor knowledge of the services and benefits that are available. Several other authors have emphasized the need of post discharge support (Andersen et al. 2002; Wilkinson et al. 1997) and a need for continuing patient education (Martin et al. 2002). There is some evidence that information combined with educational sessions improved knowledge and was more effective than providing information only (Forster et al. 2001).

Community integration and family

One of the most important elements of stroke rehabilitation, and likely the most underestimated area, is community integration. Failure to mobilize adequate support in the community can potentially negate the best efforts and results of stroke rehabilitation (Bhogal et al. 2003). The important role of family support and caregiving is becoming increasingly recognized. Marital status and social support have been found to be important predictors of discharge destination (Meijer et al. 2004). Return to a community residence after an acute hospitalization for stroke can be difficult for the stroke survivor and family alike. At this time, the person has to assume increased responsibility for independent functioning with support from the family or others (Bhogal et al. 2003). However, caring or supporting a stroke patient can often be burdensome to the caregiver (C. S. Anderson et al. 1995; Bugge et al. 1999; Dennis et al. 1998; N. J. van Exel et al. 2005; Wyller et al. 2003) and affects family functioning. There is evidence that improved social support as an intervention improves outcomes and that an active educational / counselling approach has a positive impact on family functioning post stroke (Bhogal et al. 2003). Training caregivers of stroke patients in basic nursing and facilitation of personal care techniques also reduces costs and caregiver burden while improving psychosocial outcomes in caregivers and patients at one year (Kalra et al. 2004).

Several studies have tried to identify the factors that have the greatest impact on the subjective caregiver burden and have not found significant relationships with physical disability (C. S. Anderson et al. 1995; Dennis et al. 1998). Scholte op Reimer et al. (Scholte op Reimer et al. 1998) noted that partners of stroke patients perceived the greatest caregiving burden in terms of feelings of heavy responsibility, uncertainty about the patient's care needs, constant worry, restraints in social life and feelings that patients rely on only their care. The sense of coherence of the caregivers, which refers to one's ability to respond to stressors, has also been found to relate to the degree of burden and indicates that factors other than the direct effect of the stroke influence burden (Forsberg-Warleby et al. 2002; Nilsson et al. 2001).

Study design

A randomized controlled trial with a blinded assessor was performed. This type of design has become the "golden standard" in developing and testing of drugs. It is widely considered the most reliable form of scientific evidence because it is the best known design for eliminating the variety of biases. In a randomized controlled trial, one researcher allocates a series of numbers to two different treatments in order to obtain two randomly selected groups. In the work of this thesis, two different rehabilitation approaches directly following discharge were tested and the participants were asked not to reveal to the assessor their group allocation. There are different ways of carrying out a randomization; in this work, a block design randomization was chosen to avoid having all persons in the

same treatment group at the same time. A power analysis was made to establish the number of participants needed to detect a true difference between the groups.

Cost

Cost efficacy must be taken into consideration when priorities are set within the limited resources for health care. Several studies have investigated the incidence / prevalence and cost of stroke (Truelsen et al. 2005)(Ghatnekar et al. 2004)(Ghatnekar et al. 2004)(Grieve et al. 2000)(Claesson et al. 2000) and the long term cost of illness in stroke patients (Payne et al. 2002)(Evers et al. 1997)(Terent et al. 1994). The demand for studies of cost of stroke will continue to increase over the coming years as a result of the high prevalence of stroke and the frequent long term consequences of survivors' disabilities, which represent a substantial socioeconomic burden associated with the disease. There is also a need for more detailed studies of data specific to the location of care and the resources consumed. To allocate health care resources in an efficient way, policymakers require information on the costs and outcomes of competing health care interventions (Maynard and Kanavos 2000) as well as the factors that influence costs (J. Van Exel et al. 2003). Known important determinants of costs are disability status and having a partner. Disability is an umbrella term in the ICF and there may be a need to go into greater detail concerning which factors are the main cost drivers. In order to do that it is important to determine from which of the ICF categories (impairment, activity limitations or participation restrictions) from which the most important information may be obtained. It is also important to have knowledge of when it is possible to make generalizations for a whole population and when to make a separation into subgroups, such as age (working age / retired). As mentioned, there are differences in needs between age groups. The cost may vary from different studies as the costs are defined in several ways.

AIM

The overall aim of the thesis was to describe and evaluate different aspects of the rehabilitation after stroke in persons of working age, to compare two different approaches of rehabilitation after discharge and to describe the costs and factors that influence costs associated with stroke in persons of "younger" age.

Specific aim in Study I

To be able to use the European Brain Injury Questionnaire, EBIQ, as an evaluation tool, the aim of study I was to examine the reliability and validity of EBIQ for use for this purpose in a stroke sample.

Specific aim in Study II

To evaluate whether three weeks of support, information and training in the home setting to transfer skills achieved in hospital into the home environment would better improve activity than ordinary outpatient rehabilitation at the clinic.

Specific aim in Study III

To evaluate whether an intervention with information about stroke and its consequences to patients and next of kin together with practical advice and training in the home setting would reduce or affect the burden of care for next-of-kin in the home group compared to that for the next-of-kin of the stroke patients in a day clinic group receiving ordinary rehabilitation.

Specific aim in Study IV

The aim was to describe the direct and indirect costs of hospitalization and rehabilitation in the first year after a stroke in "younger" persons (<65 years) and to examine the factors that contribute to higher costs.

METHODS

Patients

All patients with a first occurrence of a focal stroke at the rehabilitation ward, Sahlgrenska University Hospital, were asked to participate in a randomised controlled study, either in their home setting or at the day clinic. Patients referred to the rehabilitation ward are a selected group of patients of working age with a moderate to severe stroke who would benefit from intense rehabilitation. Fifty-eight patients were examined from January 1998 to December 2001. The patients were included after informed consent. The inclusion criterion was patients discharged to their own living. See fig 3 for details about the recruitment process. Ineligible patients were patients not discharged to their home. Patients who declined were either patients that had had a good recovery and did not think they would benefit from an intervention of this kind or patients with physical limitations that thought they would benefit more from the day clinic program with the possibility of training at the physiotherapy facilities. The two persons that dropped out after entering the study had changed their mind and had other things to do and accordingly did not attend any further rehabilitation. One person refrained from the one-year follow-up. There were 29 patients in each group and both groups were similar concerning age, gender and diagnosis (Table I, p 22). However, there was significantly more aphasia in the home group. The groups did not differ significantly in function or ability at baseline (discharge) on the different outcome measures used. *Study II* compared the two groups and included all the 58 patients, divided into the home group and the day clinic group. In *study I,* 54 patients who had been able to answer the European Brain Injury Questionnaire were included in the study. Thirty-six of these patients had a next-of-kin who also participated in the study (Table II, p 26). *Study III* examined caregiver burden. The same 36 next-of-kin as in study I were approached and completed questionnaires were available from 35 of them (18 in the home group and 17 in the day clinic group). *Study IV* consisted of the whole sample of 58 patients and was not divided into groups (fig 4, p 23). The Ethics Committee of Göteborg University approved the study and all subjects gave their informed consent.
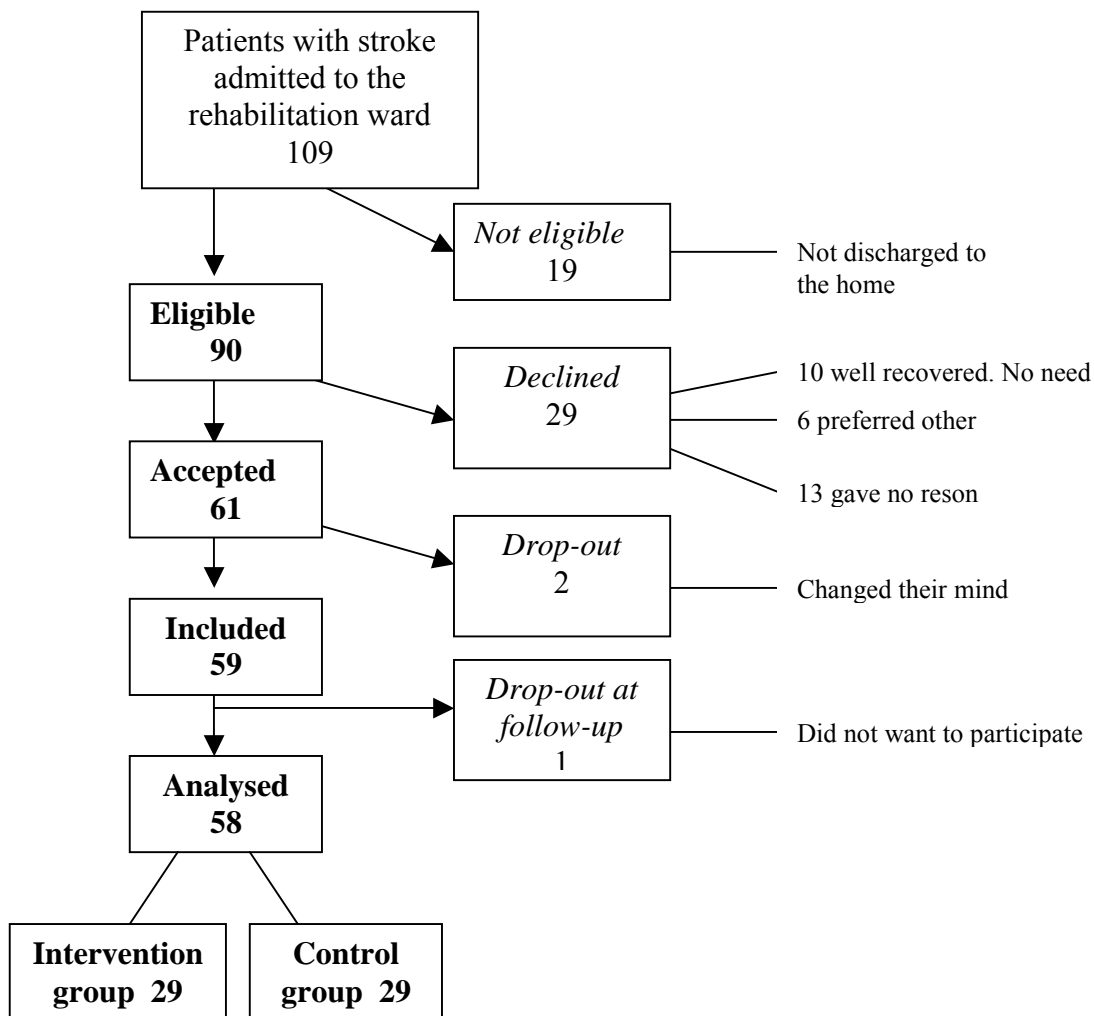
Figure 3. Recruitment process from January 1, 1998 to December 31, 2000.

Randomization and intervention procedures

The study was designed such that it would not affect the time of stay at the ward. For this reason the patients were not randomized to group until a week before discharge. The patients were distributed into the two groups by consecutive block randomization. The allocation of destination was randomly drawn from 20 sealed envelopes, in three rounds, in order to be able to control the distribution with the same number of patients in each group even if not as many patients as expected could be included.

The patients received nine hours of training per week for three weeks, either at home (home group) or at the day clinic (day clinic group), after discharge from the rehabilitation ward. The training at the day clinic consisted of three days / week. The patient met with an occupational therapist and a physiotherapist each day. There could be two to four different

sessions each day. The contents could for example be one session of training to walk, some kind of training in front of a computer to improve attention and a group session with pool exercises. An occupational therapist and a physiotherapist made home visits to those in the home group. An individual program based on the patient's needs and desires was drawn up together with the patient during those three weeks. The distribution of the nine hours of training each week could vary according to the kind of activities chosen. The week chiefly included approximately four appointments with either the occupational therapist and/or the physiotherapist. The contents of the program varied widely, from basic activities of daily living (ADL) to shopping and testing leisure activities. A great amount of time was also spent on personalised information to the patient, persons close to the patient and helpers about the stroke, its consequences and how to deal with them. After the intervention period all patients followed the usual rehabilitation process and most attended at least one period (six weeks) of outpatient rehabilitation at the rehabilitation centre during the first year after discharge.

Table I. Descriptives of the participants.

|	Intervention group N=29	Control group N=29	Total N=58
Median age	52 (28 - 61)	55 (27 - 64)	53 (27 - 64)
Men	22	22	44
Women	7	7	14
Single	12	7	19
Couple	14	19	33
Other	3	3	6
Intracerebral haemorrhage	9	8	17
Intracerebral infarction	20	16	36
Cerebellar haemorrhage		3	3
Cerebellar infarction		2	2
Left hemisphere	18	10	28
Right hemisphere	10	17	27
Bilateral	1	2	3
Aphasia	12	4	16
Neglect	8	9	17
Paretic leg	11	10	21
Paretic arm	18	16	34
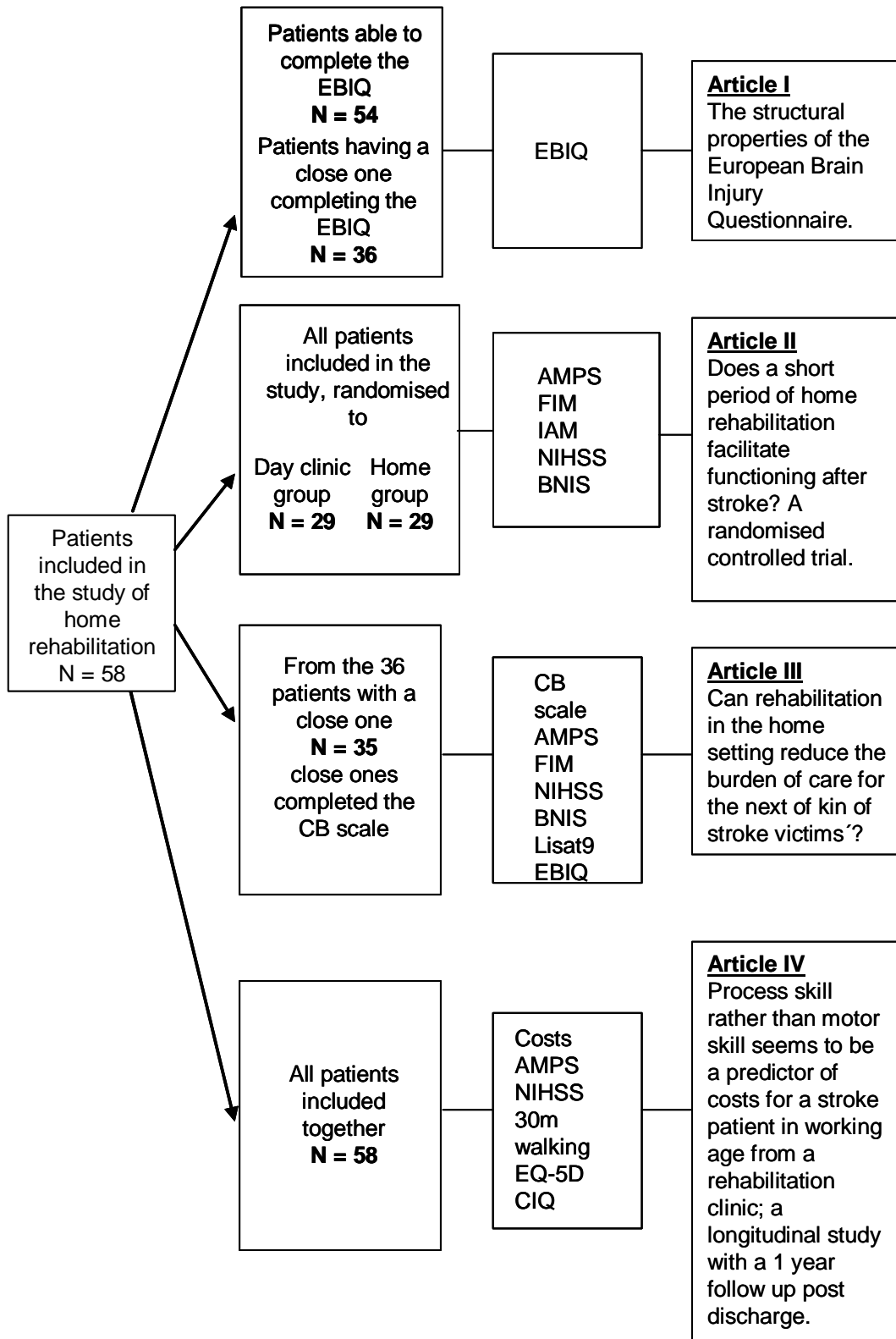
Figure 4. Participants and instruments used in studies I – IV.

Instruments

Body functions and structures

The National Institute of Health Stroke Scale, NIHSS, is a quantitative measure of stroke-related neurological deficits that has proven intra- and inter-rater reliability and has predictive validity for long-term stroke outcome. It includes items to assess level of consciousness, gaze, visual fields, facial palsy, motor strength, ataxia, sensation, language, dysarthria and extinction/inattention The scores on all items are summed with a maximum of 36. The lower the score the lesser the deficit (Brott et al. 1989).

The Barrow Neurological Institute screening for higher cerebral functions, BNIS, is a short screening test developed to systematically assess a variety of higher cerebral functions. The BNIS consists of 30 different items grouped together into seven clinically relevant factor scores with a maximum (total) score of 50. A higher score indicates better function and a score above 47 is considered normal (Prigatano et al. 1995). The Swedish version has been validated (Denvall et al. 2002).

Activity

The Assessment of Motor and Process Skills, AMPS, is a standardized assessment of occupational performance that is used to observe and evaluate a person's ability to perform personal and instrumental activities of daily living (Fisher 2003). The instrument contains 16 ADL motor and 20 ADL process skills that represent small units of the overall ADL task performance. The motor skills are the observable actions the client uses to move either him- or herself or to move objects during the performance of ADL tasks. The process skills are the observable actions of performance the person enacts to logically sequence the actions of the ADL task performance over time, select and use appropriate tools and materials, and adapt his or her performance when problems are encountered. The AMPS is designed to be used to measure the quality of a person's ADL motor and ADL process skills and is an indicator of whether the client has the skills necessary to efficiently, safely and independently perform ADL tasks needed for that client to live in the community. A rater trained and calibrated for the AMPS, having observed the client perform two or three tasks, scores each task performance. These raw scores from each task performed are then analysed using many-faceted Rasch analysis (Linacre 1993) to provide linear motor and process skill ability measures that are adjusted for a) the challenge of the task, b) the severity of the rater, c) the ability of the subject and d) the difficulty of the skill items (Fisher 1993). All measures are expressed as logistically transformed probability measures (logits), which are linear measures that can be placed on an abstract continuum of greater or lesser ability. A cut-off criteria for a person's ability to remain independent living is set at 2.0 logits for the motor skill scale and at 1.0 for the process skill scale (Bernspang and Fisher 1995a; Fisher 2003). The AMPS has been validated for use in Sweden (Bernspang and Fisher 1995b).

The Functional Independence Measure, FIM^{TM}, consists of 13 physical (or motor) and 5 social-cognitive items (Linacre et al. 1994), assessing dependence in the areas of self-care, sphincter management, transfer, locomotion, communication, social interaction and cognition. It is an ordinal scale with ratings from 1 for totally dependent to 7 for independent (Hamilton et al. 1987). A rating of 6 indicates modified independence and ratings below 6 are different levels of dependence. FIM^{TM} has been validated (Dodds et al. 1993; Kidd et al. 1995) and examined for use in Sweden (Grimby et al. 1996). (The instrument is defined as activity even if some items can also be classified as body function.)

The Instrumental Activity Measure, IAM, consists of eight items assessing dependence in common activities for community living persons, such as locomotion outdoors, simple meal, cooking, public transportation, small-scale shopping, large-scale shopping, cleaning and washing. The rating of the items follows a similar form as in the FIM, with an ordinal seven-step scale (Grimby et al. 1998).

In 30 metres walking test the client is requested to walk 30 metres at his/her own speed and the time spent in seconds is recorded (Aniansson et al. 1980; Lundgren-Lindquist et al. 1983)

Participation

The Community Integration Questionnaire (CIQ) is a 15-item scale that provides a total score for the extent of community integration (higher scores show greater integration) and subscale scores for home integration, social integration and productive activity (Willer et al. 1994). Data used are from one year post discharge.

Instruments with several components of the ICF

The EBIQ (Teasdale et al. 1997) consists of 63 questions regarding "problems or difficulties that people sometimes experience in their lives", with three alternative responses "not at all", "a little" and "a lot". The instrument can be divided into nine domains: *somatic* (described as for example headaches, lack of energy), *cognitive* (trouble concentrate, forgetting appointments), *motivation* (lack of interest in hobbies), *irritability/impulsivity* (mood swings, shouting at people), *depression* (feeling sad, crying easily), *isolation* (hiding feelings, mistrusting people), *consequences* (neglecting appearance, uncomfortable in crowds), *communication* (losing contact with friends, difficulty participating in conversation) and *core* (having problems in general). There are two parallel versions of the EBIQ, one to be completed by the patient and the second to be completed by a person close to the patient who reports his or her perception of the patient's problems. (As the instrument measures the patient's perception of functioning in relation to what is normal, it may be a description of participation but also include items of body

function in the somatic and cognitive domains as well as activities, for example problems with personal care.)

The Caregiver Burden scale (CB scale) (Elmstahl et al. 1996) is a questionnaire with 22 questions (answered in writing by the carer) concerning burden from the aspects of the caregiver's health, feeling of psychological well-being, relations, social network, physical workload and environmental aspects that might be important. When the scale was developed, factor analysis was used to yield five indices – general strain (eight questions), disappointment (five questions), isolation (three questions), emotional involvement (three questions) and environment (three questions). The general strain index was used for the analyses as containing issues possible to influence with an intervention. The items are scored from 0 to 3 (not at all, hardly, somewhat and definitely), and the maximum score is 66. (Caregiver burden can be viewed as an environmental factor.)

Quality of life

Quality of life is not included in the ICF classification as the ICF is a classification of human functioning and its restrictions. For this reason EQ-5D and LiSat9 can not be referred to as components of the ICF

Euroqol, EQ-5D, is a generic instrument for measurements of health-related quality of life (HRQOL) (Dorman et al. 1997). The EQ-5D includes a visual analogue scale on which the patients rate their own health between 0 and 100. The data used in this study are taken from the visual analogue scale at one year post discharge.

Life satisfaction by Fugl-Meyer, *LiSat 9* (Viitanen et al. 1988) consists of nine items, eight of them characterising different domains of life and one characterising life as a whole. It uses a six-point scale ranging from 1 (very dissatisfied) to 6 (very satisfied). When used in study III only the domain of life as a whole was considered.

Table II. Descriptives of the patients with a next-of-kin

	Gender		Mean age	Diagnosis				NIHSS Sum score	NIHSS Language problem
	M	F	years	Cerebral infarction	Cerebral haemorrhage	Cerebellar haemorrhage	Cerebellar infarction	Median	Cases
Patients with a next-of-kin N= 36	25	11	51	23	8	3	2	4 (0-11)	8

Assessment procedures

Evaluation was made at discharge, three weeks, three months and one year after discharge with some differences between the instruments. Figure 4 shows the participants and instruments used in the four studies.

The AMPS, FIM^{TM} and IAM assessments were performed in the patient's home setting by an occupational therapist familiar with the instruments and blinded to the group assignment. At a visit to the clinic the NIHSS was assessed by a physician, BNIS executed by a neuropsychologist and the 30 m walking test assessed by a physiotherapist, all of them blinded to the group in which the patient was included and not involved in the intervention. In study I, EBIQ assessments were performed in the patient's home setting supervised by an occupational therapist. Assessments made at discharge from the rehabilitation ward and at a one-year follow-up were analysed in this study. In study III the persons close to the patient were approached in the home setting, when assessing the patient at three weeks, three months and one year after discharge. Correlations were made with data in the other instruments used, from discharge and one year post discharge. In study IV the EQ-5D and CIQ instruments together with a checklist for recording service use were used in addition to the instruments mentioned above. Data from EQ-5D and CIQ from one year post discharge and data from discharge on the instruments of body function and activity were used in the regression analysis. Costs were calculated for the time of hospitalization after the stroke and the first year following discharge.

Data on the 29 patients who declined to participate were collected as part of the clinical routine in the FIM^{TM} and NIHSS at discharge. To be able to examine for differences between participants and non-participants, these discharge data were complemented with assessments one year after discharge from 11 of the first 12 non-participants who agreed to be assessed with the AMPS, the FIM^{TM}, the IAM and the 30 m walking test.

Data analysis

To decrease the risk of low power, a power analysis was undertaken after acquiring data on the first 20 participants in the main outcome measure (AMPS). The aim was to detect a significant difference ($p<0.05$) (using Student's t-test) between the groups of 0.5 logits (considered a clinically relevant difference) (Fisher 2003; Kirkley and Fisher 1999) after the intervention period in the process skill scale; 25 persons in each group yielded a power of 80%.

To obtain linear measures, Winsteps software was used to conduct Rasch rating scale analyses of the FIM^{TM} and the IAM (Linacre 2002). The Rasch analysis was made as one analysis for all data from all occasions with the assumption that items stay stable over time

as shown for the FIM^{TM} (Linacre et al. 1994). Results in logits were used for evaluations of group differences.

Rasch analysis was also used in study I, a methodological study that examined the psychometric properties of the EBIQ instrument. Rasch analysis allows one to re-test existing, validated instruments more strictly (Hall et al. 1993) and, as in our case as well, examine whether the instrument is valid for use for a different purpose than was originally intended. The aim was to analyse whether EBIQ was valid and reliable to use for an evaluation that is an expanded use of the instrument over simple description. The Rasch model provides techniques for evaluating the psychometric characteristic and the quality of the measures produced (Bode et al. 2000). In this study (study I) the focus was on two criteria's quality, reliability and validity. Reliability was expressed in terms of separation, separation reliability with the Rasch model and validity determined by item hierarchy, fit statistics and targeting.

In studies II and III we wanted to compare the two randomised groups and used Student's t-test for independent samples on interval data and a non-parametric test, Mann Whitney U, for ordinal data. In these two studies we also wanted to make comparisons between different occasions and, even though we wanted to compare multiple occasions, we decided to use simple statistics in order to make them more comprehensible. We thus used Student's t-test for related samples when applicable and in most cases the non-parametric Sign test. In study II we also used Kaplan-Meier survival analysis in order to demonstrate the interaction between group and time. The Kaplan-Meier curve illustrates different time points and the percentage of the two groups that had made a clinically relevant improvement at that time. To examine for eventual differences between the non-participants and the two groups of participants, comparisons were made of the FIM^{TM}, NIHSS from discharge and the assessments at one year of the AMPS, FIM^{TM}, IAM and the 30 m walking test (Study II).

In study III we wanted both to analyse for differences between the groups in caregiver burden and examine aspects related to a higher caregiver burden. For this purpose a correlation analysis was made using Goodman Kruskal's Gamma with the CB scale, general strain index, and the aspects that we assumed could relate to burden, which were physical and cognitive impairment (NIHSS, BNIS), dependence in personal care (FIM^{TM}), instrumental activity limitations (AMPS), the patient's and next-of-kin's experience of social, cognitive or emotional problems after the stroke (EBIQ) and the patient's life satisfaction (LiSat 9).

The last study, study IV, was a study of cost of stroke and we calculated the direct and indirect costs of hospitalization and service use the first year post discharge. A linear regression was done as we also wanted to explore factors contributing to higher costs. The hypothesis was that IADL ability, ability to walk and presence of aphasia were factors that might possibly influence direct costs, i.e. length of stay in hospital (LOS) and need for rehabilitation services and aids after the initial hospitalization. The IADL ability was represented by the two ability measures, motor and process skill, in the AMPS. Walking

ability was recorded with the 30-m walking test given in m/s. Aphasia was given as three categories: no aphasia, mild and severe aphasia assessed by the National Institute of Health stroke scale (NIHSS).

The hypothesis of factors influencing the indirect costs of assistance from informal caregivers included the stroke victim's perceived health related quality of life (EQ-5D), IADL ability, presence of aphasia and his/her participation in daily activities in the home (CIQ). In this study (IV), we used the CIQ subscale of home integration, which was defined as: 0-3 = not integrated and >3-10 = integrated.

Choice of content of articles in the thesis

The patient perspective of problems after a stroke is important information that is possible to capture with the EBIQ, giving the motivation for choosing this instrument. As the instrument was originally designed to be descriptive, there was a need to analyse the validity and reliability when used for evaluation in *Study I*. The measures from EBIQ analysed by Rasch were used in study III and we intend to publish an article reporting the results of the two groups and patient and next-of-kin perspective.

Study II was intended to describe the study of home rehabilitation and this approach was taken because, when the study started, there were expectations of a major impact of the intervention on activity. However, in the latest decade, primarily because of improvements in acute care after stroke, the stroke patients included in the study were less physically impaired than expected and the problems and the focus of the intervention were somewhat different.

A new instrument for caregiver burden was used in *Study III*. As the burden of care seemed to be quite substantial despite a sample of patients who had made a relatively good recovery, it was of interest to explore this aspect.

Health economics is an important area today and it was seen as important to calculate the costs in this group of younger stroke patients in *Study IV*. For this purpose the sample was not divided into the two groups; the difference in cost of the two interventions had already been analysed in study II.

RESULTS

The study included 58 patients with four assessments from discharge to one year after discharge. The sample included 36 patients who had a next-of-kin that could be involved in the assessments by answering the two questionnaires, EBIQ and the CB scale. Ten different instruments were used that covered the different components of the ICF. Table III gives data from most of the instruments in the different assessments. Direct costs for hospitalization and health services after discharge were recorded and indirect costs for informal care and production loss were estimated.

Table III. Median and mean scores in the different assessment for the two groups.

Instrument		Intervention		Follow-up	
		Discharge	3 weeks	3 months	1 year
BNIS (median, sum score)	H	40	--	40	42
	C	42	--	42	43
NIHSS (median, sum score)	H	5	--	4	3
	C	4.5	--	2.5	2.5
AMPS motor skill (mean logit)	H	1.40	1.67	1.98	2.20
	C	1.43	1.51	1.88	2.30
AMPS process skill (mean logit)	H	0.96	1.24	1.22	1.54
	C	1.18	1.35	1.51	1.57
FIM^{TM} motor scale (median, sum score)	H	77	80	83	83
	C	80	82	84	84
FIM^{TM} motor scale (mean logit)	H	2.61	3.02	3.49	3.50
	C	2.71	3.21	3.36	3.95
FIM^{TM} soc/cog scale (median, sum score)	H	31	31	32	32
	C	31	33	33	33
FIM^{TM} soc/cog scale (mean logit)	H	1.66	1.94	2.05	2.08
	C	1.86	2.31	2.41	2.66
IAM (median, sum score)	H	22	30.5	33	38.5
	C	22.5	28	32.5	38
IAM (mean logit)	H	-0.21	0.25	0.52	0.68
	C	-0.32	0.08	0.58	1.03
30 m walking test (mean velocity, m/s)	H	0.70	--	0.90	0.94
	C	0.84	--	0.93	0.98
EQ-5D thermometer (0-100, median)	H	--	--	70	70
	C	--	--	60.5	63.5
EBIQ (median, sum score)	H	86	77	80	70
	C	88	81.5	82	63.5
CB scale (median, sum score)	H	--	21	21	25.5
	C	--	30	23	18.5

Evaluation of the psychometric properties of the EBIQ instrument

The evaluation of the EBIQ (study I) showed that the reliability was good as the instrument met the criteria for separation. There was no significant difference between patients and next-of-kin in the item hierarchy. This means that the items have the same order of difficulty for both patients and next-of-kin, which makes it possible to make comparisons.

Concerning validity, the instrument met the criteria for acceptable misfit of 5 %, at discharge data (2 item), and was just above that level in the one-year data (5 item ≈ 8 %) for which reason we considered the instrument unidimensional, i.e. measured one concept. The analyses of differences across occasions were made to examine the stability of the instrument in terms of verifying that the same concept is measured on all occasions. No significant differences were found, which indicates a possibility to use the instrument for evaluation.

Figure 5 shows the item difficulty in hierarchical order for the five most problematic and five least problematic items. The five items perceived as least problematic in patient data are items dealing with aspects of behaviour, awareness of appearance and feelings of inferiority, and all seem to need a high degree of occurrence and grave behaviour before problems are perceived. They are also items that are closely connected with an aspect of awareness that is not easily obtained. However, the five items perceived as most problematic are, at least in four of the items, things that most patients with a stroke experience and recognize easily.
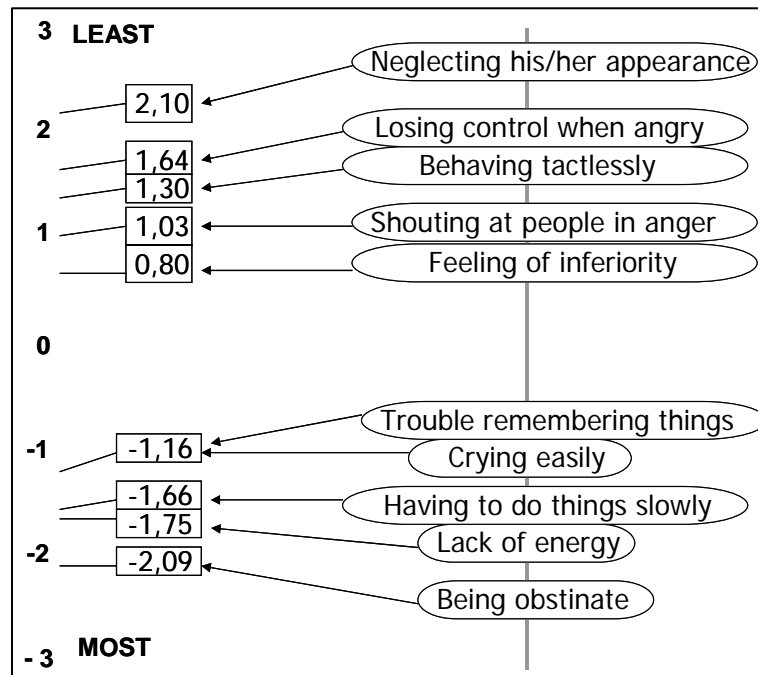
Figure 5. Item hierarchy of the five most problematic and five least problematic items.

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The targeting is visualised in figure 6 in the item and person map, where the person and item variables are positioned vertically on the same line with the most able persons and most difficult items at the top. Good tests usually show the items targeted (lined up) with the persons. This indicates the extent to which items are of appropriate difficulty for the sample. An even spread of items indicates that most regions of the variable are defined or tested. In this case the items and persons are somewhat skewed, which could indicate that the items in the instrument are too easy. However, the need for more difficult items is not obvious. Those stroke patients who have a higher ability than the range of item difficulty may simply be persons with mild or no cognitive, emotional and social disabilities that do not cause everyday difficulties.
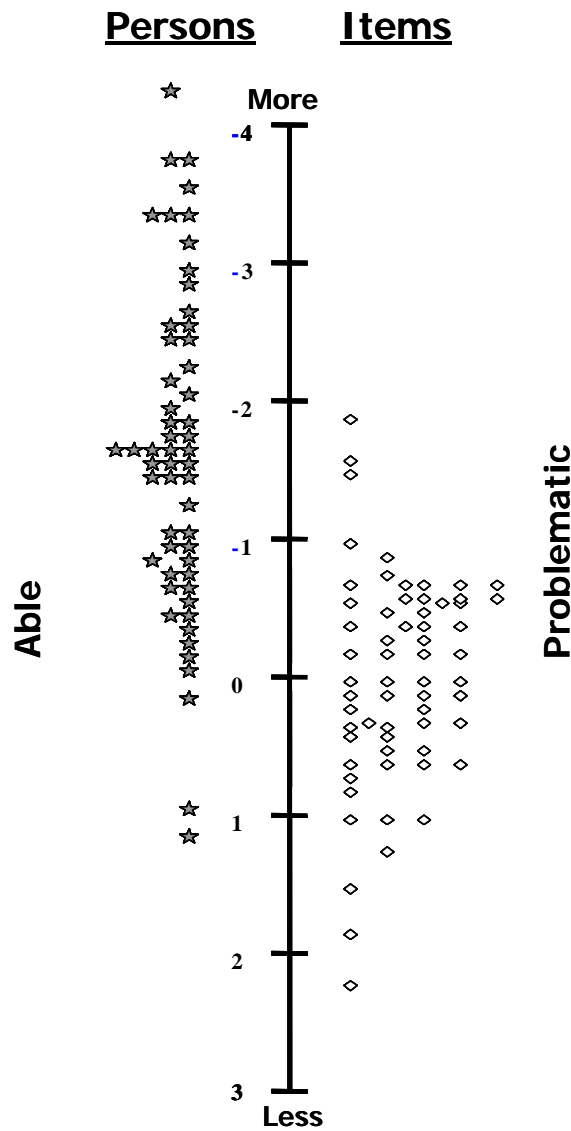
Figure 6. Item and person map showing the more able persons and the more problematic items at the top.

The item data were used to test the data as the intention was to examine whether the instrument measured the same concept in different groups, in this case patients and next-of-kin. The results showed no significant difference in the meaning of the items between patients and next-of-kin. Another aspect, not yet published, was to analyse whether patients and next-of-kin differed in their opinions of which problems the patient had after the stroke and to what extent they occurred. The results showed a great discrepancy between the opinion of the patient and the next-of-kin at three weeks after discharge (fig 7). Patients and next-of-kin differed at discharge, but not as much as they did at three weeks and, at one year post discharge, the large differences were still present. A higher proportion of patients perceived fewer problems than did the next-of-kin compared to vice versa.
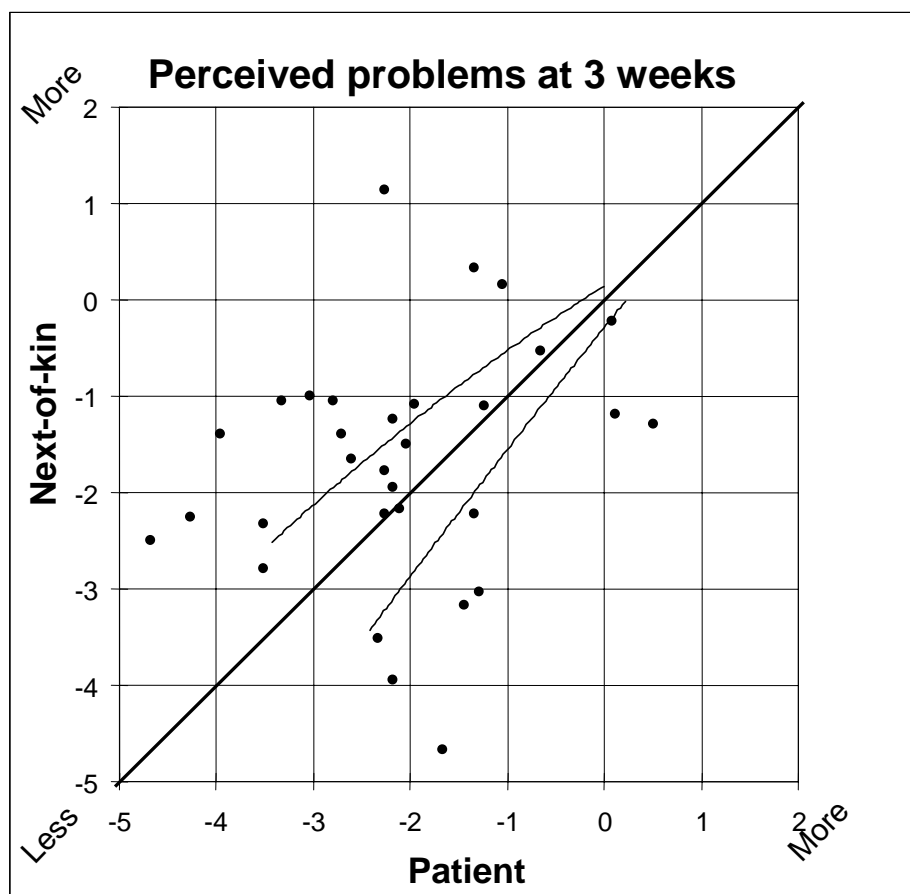
Figure 7. The figure shows the perception of social, cognitive and emotional problems (EBIQ) from the patient perspective (X axis) and that of the next-of-kin (Y axis) at three weeks after discharge. The scale is given in logits, and a lower number indicate fewer perceived problems. The two reference lines represent the 95 % CI.

Comparison between the home group and the day clinic group

As it is a challenge to decide which instruments or variables of outcome will best capture whether one intervention has an advantage over another, study II used both the instruments of body function and activity. When examined, the results revealed that both groups made significant improvements, from discharge to the one year follow-up, in activity but no significant changes in body function (table IV). The non-participants also improved during the first year after discharge, but not as much, as they had significantly fewer neurological deficits (NIHSS) and a higher ability (FIM[TM]) at discharge than the participants. There were no significant differences at the one-year follow-up as compared to the participants in the assessments of the FIM[TM], IAM, AMPS and 30-m walking test.

Table IV. The table shows significant change between occasion for instruments for body function and activity. * = $p < 0.5$, ** = $p < 0.01$, *** = $p < 0.001$

		Discharge – 3 weeks	3 weeks – 3 months	3 months – 1 year	Discharge – 1 year
AMPS motor	Intervention	**	***	ns	***
	Control	ns	***	**	***
AMPS process	Intervention	***	ns	**	***
	Control	ns	*	ns	**
FIM motor	Intervention	*	*	ns	***
	Control	**	ns	***	***
FIM soc – cogn	Intervention	ns	ns	ns	*
	Control	*	ns	ns	***
IAM	Intervention	***	ns	**	***
	Control	*	***	**	***
		Discharge – 3 months	3 months – 1 year	Discharge – 1 year	
30 m walking	Intervention	**	ns	**	
	Control	**	ns	**	
BNIS	Intervention	ns	ns	ns	
	Control	ns	ns	ns	
NIHSS	Intervention	ns	ns	*	
	Control	**	ns	ns	

(Left margin labels: **Activity** spans AMPS motor through 30 m walking; **Body function** spans BNIS and NIHSS.)

The purpose of studies II and III was to compare the two randomised groups according to body function, activity (study II) and caregiver burden (study III). No significant differences were found. However, there were indications in study II of earlier improvement in activity in the home group. The home group improved significantly from discharge to after the three-week intervention in the AMPS in both measures, motor and process skill, as well as in the IAM, while the day clinic group did not change significantly during the three weeks of intervention. Both groups improved significantly from discharge to one year post discharge in both AMPS (fig 8) and IAM.
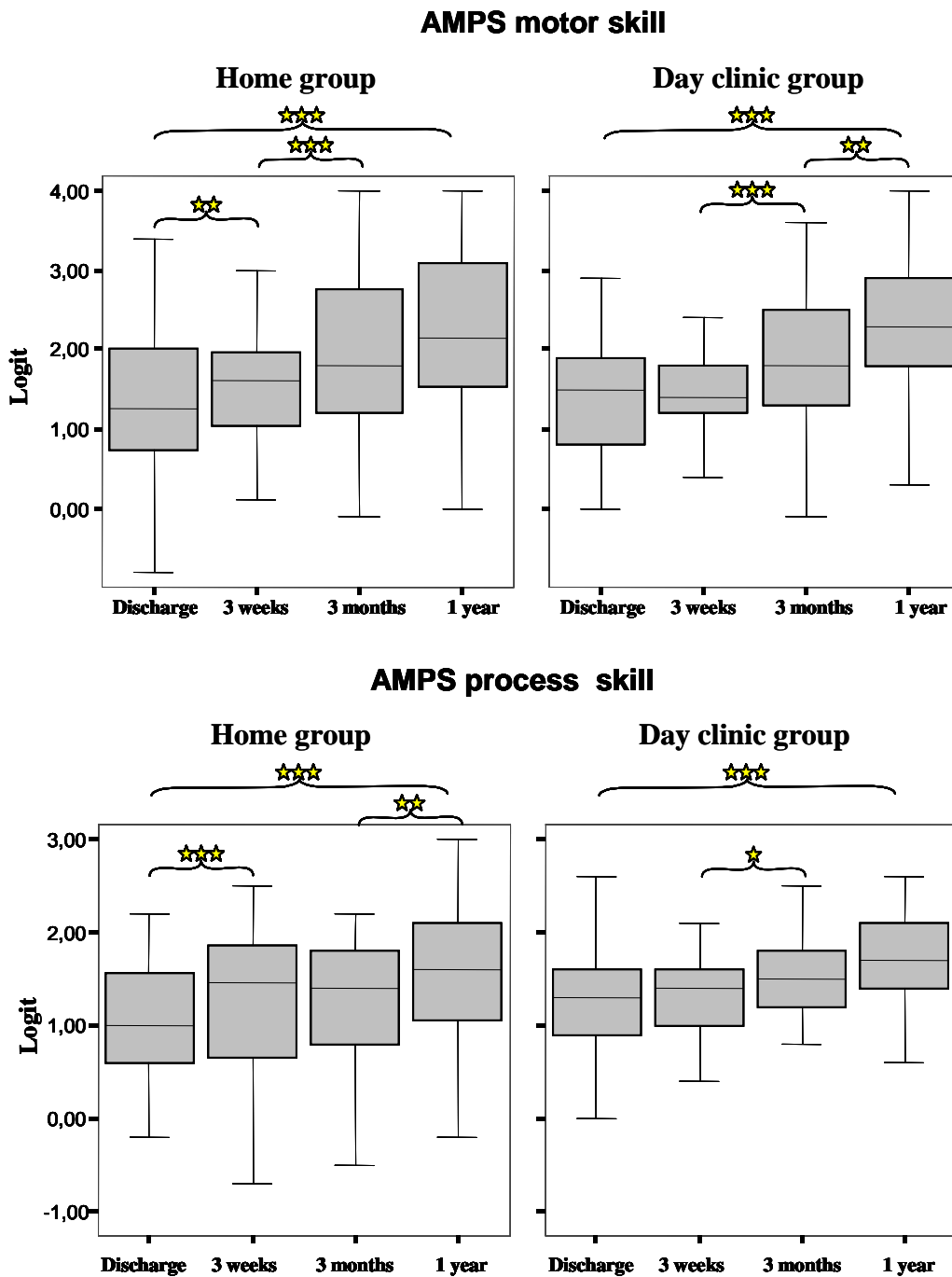
Figure 8. Box plots of AMPS motor and process skill in the two groups at the different assessment times. Boxes represent median, 10th, 25th, 75th and 90th percentiles. Significant change is marked as follows: $p < 0.5 = *$, $p < 0.01 = **$, $p < 0.001 = ***$.

Study III dealing with caregiver burden showed no significant differences between the groups in burden at any of the assessments, but there seemed to be a small difference in burden between the groups at three weeks (after the intervention) that was not large enough to be significant. The tendency was that the next-of-kin in the home group experienced less burden than next-of-kin in the day clinic group. From that point after the intervention, the next-of-kin in the home group stayed on a similar level during the first year after discharge. This was in contrast to the next-of-kin in the day clinic group, who showed a tendency toward a higher burden after the first three weeks of intervention and a change toward a smaller burden over time (fig 9). The two groups also differed in the aspects affecting the burden. In the home group the aspects were closely connected to disability after the intervention, while no such correlation was found in the day clinic group. This may perhaps be explained by the lack of information and guidance of the caregivers in the day clinic group, where feelings of heavy responsibility and uncertainty about the patient's care needs may independently affect burden. The results were somewhat surprising as so many caregivers acknowledged a burden, despite the fact that this sample of patients had recovered quite well neurologically, with a median score on NIHSS of five (maximum of 36, with a lower score showing a smaller deficit) All but one of the next-of-kin acknowledged burden at the first assessment in at least some of the questions concerning caregiver burden. The median sum score was 27 (0-52) at three weeks, 21 (0-50) at three months and 19 (0-45) at the one-year follow-up (max 66).
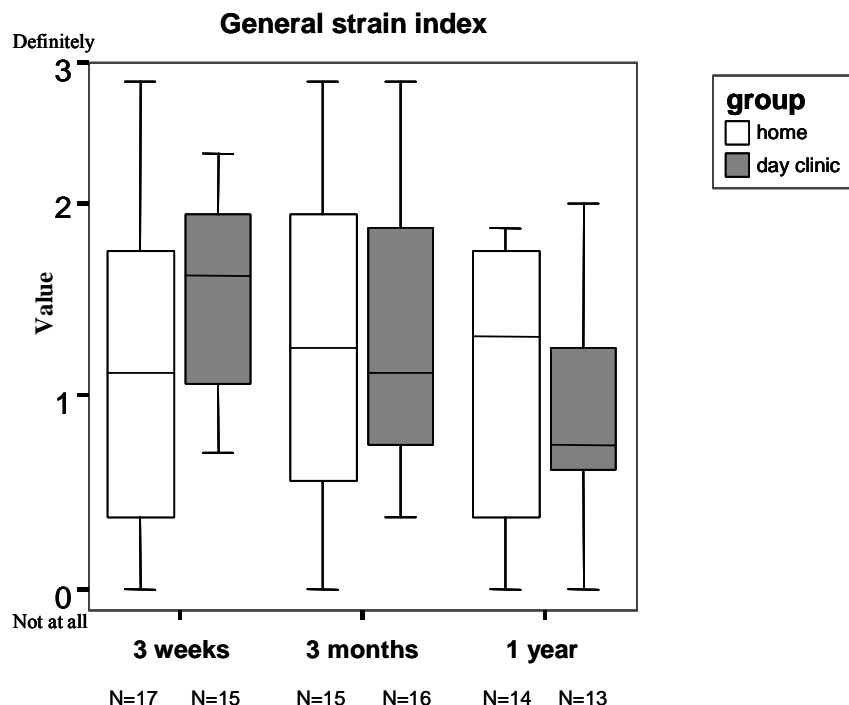
Figure 9. The figure shows boxplots for the two groups of the "general strain" index of the CB scale at the different assessments, 3 weeks, 3 months and 1 year. Boxes represent median, 10 th, 25 th, 75 th and 90 th percentiles.

Cost analysis

Study IV investigated cost of stroke including direct and indirect costs and study II calculated the costs of the two different interventions. The total cost in the home group was 1830 € and the total cost in the day clinic group was 4410 €. This gives a difference between the groups of 2580 € i.e. the costs in the home group were less than half (42 %) of the costs in the day clinic group.

In total, an average direct and indirect cost for a stroke patient including cost for hospitalization after the stroke and costs during the first year after discharge was 112 163 € in the sample in the present study (study IV). In study IV comparisons were made between the sample of stroke patients in working age from the present study and elderly stroke patients, age > 70 years (Claesson et al. 2000), in order to identify whether there were any differences between the age groups. In the study of "younger" (<65) patients the mean length of stay (LOS) in hospital after the stroke was 92 days (acute care 29 days) at a mean cost of 46 446 €, compared to the study of Claesson et al. (Claesson et al. 2000) of elderly stroke patients in the same hospital, where the mean LOS was 28 days (acute care 11 days). The average LOS after a first stroke event in Sweden is 28 days (Ghatnekar et al. 2004). The extent of outpatient rehabilitation in a day clinic also differed between the younger and older stroke patients. The elderly patients received an average of less than three days per patient of outpatient rehabilitation from discharge to 12 months, as compared to 28 days in the younger group.

Study IV also examined factors affecting the costs. The factors found to significantly affect the cost were AMPS process skill, which with one logit higher ability decreased the cost by 16 920 €, and presence of aphasia, since the cost for a patient without aphasia was 34 165 € less than for a patient with severe aphasia. Interestingly, motor skill was not found to significantly affect the cost, although this often receives the most attention.

This thesis has attempted to emphasize the situation of the next-of-kin from different perspectives. This was done in study III by addressing caregiver burden, in study I by looking at both the patient and next-of-kin perspective of problems found in EBIQ and in study IV by examining factors affecting the cost of informal care (time helping the patient). The factors found to affect the cost of informal care were not directly related to aspects of body function or ability but instead to reflect the extent of home integration and the patient's perceived health. There was a mean number of 15 hours per week of assistance but there was great variation, ranging from no assistance to 63 hours per week (1 ½ full time employment).

Evaluation of HRQOL

Study IV used the EQ-5D and found it to be of significance for the cost. There was a great variety in perceived health in the sample with a mean of 66 (15-100) at one year post discharge and no difference was found between the groups (fig 10). The domain of life as a whole (from LiSat 9) was at the same time dichotomized into not satisfied (1-3) and satisfied (4-6). It was found that 84 % of the sample was satisfied with life as a whole. The percentage of satisfied patients in the home group was 93 % and in the day clinic 75 %; this seemed to be a large difference but was not found to be significant (p = 0.071).
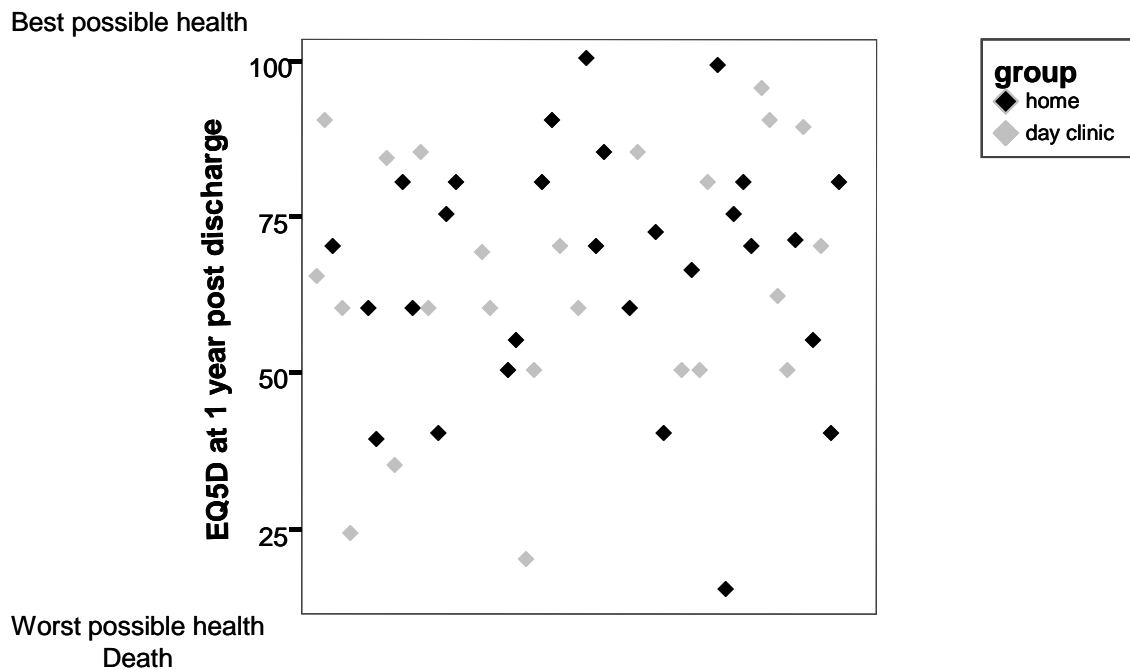
Figure 10. Scatterplot of the perceived health (EQ-5D) for all individuals in the two groups of the sample at one year post discharge.

GENERAL DISCUSSION

This work showed that an intervention may affect several aspects of outcome. When the intervention is undertaken in the post acute phase the greatest improvement occurs in activity and participation, as the greatest gains in body function have already been made. The importance of motor skill may be overestimated as other factors (process skill and presence of aphasia) were found to significantly affect the LOS and thereby costs. The caregiver burden was quite high in this sample of relatively mild strokes, indicating that other aspects than neurological ones influence the burden, such as constant worry, feelings of heavy responsibility, uncertainty about the patient's care needs and restraints in social life. The present study also demonstrated that, with an approach in the home setting of information and guidance to patients, next-of-kin and helpers, other factors were most important in terms of the burden of the caregivers in the home group, than were identified in the approach at the day clinic. In the examination of the EBIQ instrument, the underlying concept of the instrument was found to be the same for patients and next-of-kin, although there was a difference in the perception of which problems the patient had after the stroke and the extent to which they affected the patient's life. With the finding that the instrument measures the same concept, it is reliable to compare the perception of problems among patients and next-of-kin. The difference in view that was found could reflect an unawareness on the part of the patient or a difficulty among the next-of-kin to understand and experience some of the problems, an issue that will be further explored in future work. Another aspect of this work is that it has indicated the importance of tailoring rehabilitation according to the needs of the individual. Needs may be different among younger and older patients, which can hopefully explain the difference in resource allocation to younger and older stroke patients, as the result of study IV demonstrated.

An obstacle in clinical trials dealing with rehabilitation is the difficulty of obtaining large samples when the study is conducted at one single clinic and is not a multicenter study. If there is also a need to delimit the study to a certain age group and diagnostic group, the possible study population decreases. The sample in this thesis was patients in working age (18-65 years) with a first occurrence of stroke, who were referred to the rehabilitation clinic at Sahlgrenska University Hospital and discharged to their own homes. From the start of the study in January 1998 to the end of inclusion in December 2001, a total of 109 patients were eligible. Nineteen of these patients were not discharged directly to their own homes. Of the 90 patients left, almost a third did not wish to participate. As there was a significant difference in functioning between participants and non-participants at discharge, with fewer deficits among non-participants, most probably made a relevant choice as the intervention did not focus on their needs. Among the remaining 61 patients there were three further drop-outs, giving a final number of 58 patients. We made a power analysis of the AMPS process skill, and 25 patients in each group were estimated to give sufficient power (an 80% chance of finding a difference of 0.5 logits). However, as it is

generally advisable in early stages of treatment research to study multiple outcomes (Whyte 2003), we have several outcome measures and the number of patients needed to obtain sufficient power for one instrument may not be applicable for the other instruments. The comparisons between groups have not been significant in any of the analyses and may be a result of a small sample as well as of a design where two good alternatives are compared, which requires greater differences than comparisons of treatment and no treatment. We were asked in the work reported in paper II to make an intention to treat analysis (ITT), which added two persons; these first agreed to participate but then withdrew their consent and one additional person refused to participate in the one-year final assessment. It is not entirely clear how an ITT analysis should be made. We added 0 for those persons. Another way may have been to guess data, which would have been possible only for the third person for whom we had prior assessments. Owing to these difficulties, we did not use ITT in the work reported in the other papers.

The ICF was used in this thesis as a frame of reference and an aid in structuring the different outcomes. It was useful for those purposes and provided a unified language to describe the outcomes. By using the ICF terminology, the thesis has been able to show (study II) that it is more relevant in the post-acute phase to use outcome measures of activity and participation rather than body function. There was no significant change in body function from discharge to one year post discharge, while a significant improvement was seen in all instruments in activity. This may also lead to a conclusion as to how to intervene with a focus on the individual's needs in terms of activities of daily life. The results showed a tendency toward earlier improvement with the approach of rehabilitation in the home setting, which may perhaps have been a result of the above focus combined with the rehabilitation taking place in the natural context. The rehabilitation process should aim to facilitate a return to earlier daily activities, and the best way to do that may be in the context in which they will be performed in the future (Hasselkus 2002). The use of the ICF as a framework for classifying the instruments has some limitations, as few instruments are available that measure participation and several of the instruments used in this study were not developed with the ICF in mind and did not purely measure one category. In addition, quality of life is not a concept that is included in the ICF; thereby it was not either possible to refer to that aspect as a category of the ICF.

In practice we often observe that clients with similar deficits or the same disability have remarkably different results from therapy. Some appear to respond quite well, adapt readily to changes in their lifestyle and experience favourable outcomes. Others have a more difficult time. Clearly, factors other than the nature of severity of the condition, or even the type of intervention, account for these differences (Christiansen 1991; Cohen and Lazarus 1979). The idea of the study was thereby raised and one of the overall aims became a comparison of two different approaches of rehabilitation after discharge with one focusing on the adaptation to the altered life situation. The interest here was to explore

whether adaptation to conditions after a stroke could be enhanced by an approach in the home setting. The thesis has tried to show that the approach enhances adaptation among both the stroke patient and the next-of-kin. There is no clear evidence, but there seems to be an advantage for some persons, as the patients in the home group tended to improve more rapidly and the next-of-kin to cope better with the situation as the burden was related to the patient's limitations.

The rationale for "home rehabilitation" differs. In the case of Early Supported Discharge the main purpose is to free hospital beds and reduce cost (Early Supported Discharge Trialists 2005). An intervention of this kind in the home setting would be expected to give an outcome that is the same or better than that a comparative intervention at the clinic. However, the intervention is not based on an underlying hypothesis that the context contributes to a better outcome. This is in contrast to the present study, which employed a theoretical basis that the context would have an impact on outcome. It is difficult for that reason to make comparisons with the present study and ESD trials other than to support the notion that home rehabilitation is at least as good as rehabilitation at the clinic. Grasel et al. (Grasel et al. 2005) addressed the problems of transition from hospital to the home and investigated the effects on functional status of stroke patients and the health of the carers of an intensified transition concept. The concept consisted of a preparatory period before discharge including therapeutic weekend care, bedside teaching and structured information for relatives. The results showed no significant differences between the intervention and control group in the functional status of the stroke patients or the health of the caregivers. However, the same authors made a long-term follow-up (Grasel et al. 2006) from which they could conclude that an intensified transition program can sustain home care by reducing institutionalization and mortality. This approach resembles that in the present study with the difference that the context is not seen as a significant factor. Another similarity is that there are only tendencies toward a better outcome other than the in long term. The same tendencies were reported by Andersen et al. (Andersen et al. 2002), indicating tendencies toward improvement in the intervention group in the measures used. The problems in those studies and the present one are the uncertainty as to what areas exactly are influenced by the process of adaptation. e.g. body function or activity/participation, and how to assess this. A study conducted in Great Britain compared domiciliary and geriatric day hospital care in order to investigate cost effectiveness, where there was an expectation that domiciliary care could have the advantages of greater involvement of the informal caregiver and a natural context (Roderick et al. 2001). No significant differences were found. All of the mentioned studies were randomized, and all conclude that the intervention group had a tendency to be better, although it was not possible to make a subgroup analysis in any of the studies. The conclusion is thus that the intervention is probably better for some patients, but it is not certain which patients benefit.

Stroke is an injury to the brain that may affect both motor and cognitive functions. Cognition is generally defined as the individual's capacity to acquire and use information in order to adapt to environmental demands. Environmental adaptation involves using information that has been previously acquired to plan and structure behaviour for goal attainment (Lidz 1987). In study IV one of the main factors for higher cost was found to be the process skill, which can in part be explained as the ability for environmental adaptation. We can possibly conclude be that an enhancement of environmental adaptation may reduce the costs to the health care system. The ability of an individual to process information and adapt to demands may depend on the type of environment (social, physical, cultural). More familiar physical or cultural environments can influence the individual's ability to process information. Familiar environments provide contextual cues that can facilitate the access of previous knowledge and skills and guide in the selection and processing of new information (Abreu and Toglia 1987).

A significant number of brain-injured clients are unaware of their limitations in task performance (S. W. Anderson and Tranel 1989), and diminished awareness affects the ability to learn from one's mistakes and use feedback to modify behaviour in order to adapt (Barco et al. 1991). Variables that are present in an individual, such as pain, balance and awareness, cannot be measured directly (hence the term "latent" variables). They are usually assessed by measuring related behaviours, defined by sets of standardized items (Tesio 2003). It is quite difficult to define the set of behaviours that is related to awareness and there are thus not many instruments available. Three main methods have been used to assess awareness: clinician ratings, participant/informant discrepancy scores and objective test/self-rating discrepancy scores (Hardy et al. 2006). The work reported in this thesis used the participant/ informant discrepancy method with the EBIQ, comparing the patient and next-of-kin view of social, cognitive and emotional problems. The results are not easily interpreted, however, as it may either be the patient that lacks awareness of the problems or the next-of-kin that has difficulty understanding or observing problems that are not obvious. In the comparison of EBIQ, there were both some of the next-of-kin that perceived less of a problem than the patient and a somewhat larger proportion of patients that perceived less a problem than the next-of-kin (fig 7). At discharge, only one next-of-kin perceived a lesser problem than the patient. This might be because the patient had until then stayed in hospital and the next-of-kin was not present to witness the improvement or had only a vague idea about how the impairments would affect activity and participation and thereby thought it would be very problematic. There was a majority of patients in all assessments who perceived lesser problems than the next-of-kin. This may be a consequence of unawareness but may also be a consequence of the patient feeling confident in terms of how he or she could handle problems.

The "successfulness" of rehabilitation also depends on personal factors in the person with stroke. One such factor is age. Survival time after stroke varies. Society places

different demands on people of different ages. Returning to home is considered to be natural for a young person of perhaps 50 but not always for a person of 85. It has been estimated in England that 25 % of all people with stroke living in community housing will be under the age of 65 (Kersten et al. 2002). Many of these younger people survive their stroke for longer periods.

As a consequence of their age, younger people with stroke have to deal with issues such as loss of employment and family activities, e.g. raising children (Kersten et al. 2002). The major disability in young survivors of ischemic stroke is in work activity, since most patients are independent in personal activities of daily living (PADL) but many do not return to work (Varona et al. 2004; Vestling et al. 2003). Increased mental fatigability and concentration and impaired stress tolerance are some of the symptoms of the astheno-emotional syndrome, a known consequence of stroke that may especially affect the possibility for the younger stroke patient to proceed with his or her everyday life as it was before the stroke (Carlsson et al. 2004). A limitation in the work reported in the thesis is that it has not specifically addressed these aspects. However, data have been gathered both on perception of social, cognitive and emotional problems from the EBIQ and on health-related quality of life from the LiSat9 that will be presented in the future, hopefully giving useful information on the subject. The definition of stroke according to mild, moderate or severe is principally founded on motor function and ability in PADL but seems to be insufficient with respect to the aspects above (Carlsson et al. 2003). A similar conclusion was made in study IV here, as the significant factors affecting cost were aphasia and process skill. There are differences in needs among younger and older patients, and perhaps different measures should be used for evaluation of the rehabilitation. While there is already a difference in the services provided for the different age groups, there is still a limited amount of studies describing these differences, as they have largely focused upon people over the age of 65 years (Kersten et al. 2002).

Costs must be taken into account. In study II we showed that the intervention group made the same gain as the day clinic group over the first year but improved faster and at a lower cost. In study IV a comparison was made between resource uses in younger versus older stroke patients. Figure 11 shows the different resources utilized in the population studied in this thesis compared to the older population from Göteborg (Claesson et al. 2000), where the costs in the latter study were recalculated to the costs of 2004. The last sum includes both hospital costs and costs to society due to production losses, which are of course higher for those in working age. Both costs for hospitalisation and the total cost are approximately six times higher in the younger group and the length of stay in hospital three times longer. The older group received hardly any day clinic rehabilitation, which is notable. As argued above, the younger group has special needs that must be addressed and seems for that reason to have received more rehabilitation. However, the older group may have received less than they need.

A comparison of younger and older stroke patients		
	Younger group < 65 years	Older group > 70 years
Hospital, acute care	29 days	11 days
Hospital, rehabilitation	63 days	17 days
Total initial hospital care	92 days	28 days
Day clinic rehabilitation	28 days	< 3 days
Hospitalisation cost	428 076 SEK	75 739 SEK
Assistance Home assistant Personal assistant	9 372 SEK 48 325 SEK	19 513 SEK
Informal care / support	24 676 SEK	17 707 SEK
Total direct and indirect cost	1 033 761 SEK	186 042 SEK

Figure 11. A comparison of services and costs between younger and older stroke patients (Claesson et al. 2000). Costs are given in Swedish crowns (SEK) in 2004 price levels. Total direct and indirect cost in the present study includes hospitalisation time and one year after discharge, and in the older sample a total of one year including hospitalisation.

Quality of life can be affected by the health situation, independence in different situations including ADL, living quarters etc. Data from other studies on the elderly do not lend themselves to conclusions on quality of life in relation to these factors. Carlsson et al. (Carlsson et al. 2003) show in their study of younger persons with stroke that quality of life is lower as compared to norm values. One can speculate that the quality of life among older persons with reduced ADL ability might have been higher if they had received more rehabilitation efforts, thereby also eventually increasing costs.

FURTHER STUDIES

- To analyse the aspects of self-awareness (EBIQ) and quality of life in this sample.

- To assess an eventual relationship between cognitive function (BNIS) and process skills (AMPS).

- To consider the aspects of community integration (CIQ) on quality of life and the aspects of self-awareness (EBIQ) on community integration.

- To study adaptation where self-efficacy is assessed.

CONCLUSIONS

In this thesis it is shown that the home group tended to improve more rapidly in the main outcome, the AMPS. Rehabilitation in the home setting may therefore be offered as an alternative to traditional day clinic rehabilitation, since it is less costly and may be a way of speeding up the rehabilitation process. The burden of care seems to be lower in the home group in the short term. This was probably due to tailored information on how to meet the person's needs and how to give the right kind of support. Carrying out an RCT is difficult but can be done. Choosing the "right" outcome measures requires a great deal of searching and thorough analyses. An outcome measure sometimes needs further analysis to determine whether it is suitable for follow-up studies. This was done with EBIQ in this thesis. Power analyses should be made of the main outcome. If possible, secondary outcomes should also be analysed. A larger group would have made subgroup analysis possible. An intervention should show results, but costs must be considered in order to be able to make priorities. In tax financed health care, an evidence based intervention that is cost-effective should be financed.

POPULÄR VETENSKAPLIG SAMMANFATTNING

Insjuknandet i stroke sker ofta plötsligt. För personen som drabbas är det en livskatastrof som innebär stora förändringar både initialt genom diagnostisering och utredning av de konsekvenser sjukdomen inneburit och senare i den process som vidtar med behandling och rehabilitering. Även efter behandling kan personen ha kvarstående nedsättningar som innebär begränsade möjligheter att fortsätta livet på samma sätt som tidigare. Därför är det är viktigt att rehabiliteringsinsatser fokuserar på rätt saker, vid rätt tidpunkt och i rätt sammanhang och omgivning för att personen som drabbats ska kunna anpassa sig till de nya förutsättningarna. Det är också viktigt att betydelsefulla personer runt den som drabbats blir involverade i rehabiliteringen och att de liksom den drabbade får adekvat information och stöd. För att kunna erbjuda en så bra rehabilitering som möjligt är det även väsentligt att utvärdera och pröva olika metoder och infallsvinklar för rehabilitering. En förutsättning för att kunna göra bra utvärderingar är att man har bedömningsinstrument och frågeformulär som ger bra och rätt information kring väsentliga frågor.

Syftet med avhandlingen var att beskriva och utvärdera olika aspekter av rehabilitering efter utskrivning från sjukhus för personer i arbetsför ålder som drabbats av stroke. Målet var att beskriva två olika typer av insatser där den ena var inriktad på att i den strokedrabbade personens hemmiljö erbjuda stöd, information och träning till den som drabbats samt till de närstående, och den andra insatsen erbjöd träning genom dagrehabilitering på klinik hos sjukgymnast och arbetsterapeut. Kostnader och faktorer som var av betydelse för kostnader skulle även beskrivas.

Metod: De 58 personer som ville delta i studien delades när de skrevs ut från sjukhuset genom lottning till två grupper, en hemträningsgrupp (29 personer) och en dagrehabiliteringsgrupp (29 personer). Därefter fick samtliga 9 timmar träning per vecka i 3 veckor antingen i hemmiljön eller på klinik beroende på grupptillhörighet. För att kunna utvärdera insatsen gjordes bedömningar och frågeformulär innan de 3 veckornas träning och efter träningsperioden. Därefter följdes personerna under 1 år och bedömning gjordes även efter 3 månader och 1 år. Det kan vara svårt att exakt veta vad som kommer att påverkas genom en insats och därför valde vi att ha en bredd på de instrument som användes och utgick från WHO's klassificering av funktionstillstånd, funktionshinder och hälsa, ICF. Det område som fick huvudfokus var aktivitet och därför valdes bedömningsinstrumentet Assessment of Motor and Process Skill (AMPS) till huvudsakligt instrument för att mäta utfallet av rehabiliteringen. Förutom mått på kroppsfunktion, aktivitet och delaktighet undersöktes även bördan för närstående genom frågeformuläret Caregivers burden scale (CB skalan). Kostnaden för samhället genom sjukvård, rehabilitering och andra insatser beräknades för tiden personen vårdades på sjukhuset och det första året efter utskrivning. Genom att göra en regressionsanalys med kostnaden och andra bedömningsinstrument gjordes ett försök att hitta förklaringar till vad som orsakar högre kostnader. Då det är väsentligt med bra instrument som kan mäta det man önskar

mäta gjordes även en undersökning av instrumentet European Brain Injury Questionnaire (EBIQ) för att se om det gick att titta på hur denna upplevelse förändras över tid förutom att enbart beskriva de olika sociala, kognitiva och emotionella problem en person med hjärnskada kan uppleva.

Resultat: Det sker en hel del förbättringar under det första året efter insjuknande. I denna post-akuta fas när mycket av spontan läkning av förlorade kroppsfunktioner redan skett är det fr a i aktivitetsförmåga man ser de största förbättringarna. En jämförelse av kostnader för de två olika insatserna visade att hemträningen var mindre än hälften så dyr. Många av de närstående upplevde börda trots att personen fysiskt var relativt väl återhämtad, beroende på det ansvar man får ta, osäkerhet om hur man ska stötta och hjälpa samt att insjuknandet är en händelse som i stor utsträckning påverkar livssituationen. De undersökta personerna som var i arbetsför ålder hade i medeltal 92 dagars inläggning på sjukhus efter insjuknandet vilket innebär betydande kostnader. De faktorer som befanns ha betydelse för en högre kostnad var om man hade drabbats av afasi och om process färdigheterna var låga (förmågan att planera och utföra en uppgift och anpassa för de problem som uppstår under utförandet). Undersökningen av instrumentet EBIQ visade att det har lovande egenskaper och lämpar sig för utvärdering över tid.

Slutsats: Rehabilitering i hemmiljön verkar minska bördan hos närstående samt ge lägre kostnader. Båda de undersökta insatserna kan rekommenderas men ytterligare studier bör göras för att kunna säkerställa vilka personer som speciellt kan dra nytta av träning i hemmiljön. Det kan finnas olika behov hos yngre (< 65) respektive äldre som drabbats av stroke, vilket kan vara en förklaring till att dessa grupper tilldelas olika mängd resurser. Denna avhandling visar på en del orsaker till skillnaden mellan yngre och äldre, men det kan vara viktigt att ytterligare undersöka hur och varför resurser fördelas som de gör samt att göra avväganden om det sker på bästa sätt.

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