Rehabilitation after stroke with focus on early supported discharge and post-stroke fatigue

Anna Bråndal

Department of Public Health and Clinical Medicine, Medicine
Department of Community Medicine and Rehabilitation, Physiotherapy
Umeå University, Umeå 2016

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To my family, Tomas, Rut, Tyra and my schnauzer Grim

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Abstract

Background Stroke is a major cause of disability worldwide. After treatment in a specialized stroke unit, early supported discharge (ESD) followed by home rehabilitation has shown to be an effective way to improve patient outcome and quality of care for persons with mild to moderate stroke. ESD service is recommended in the national and international guidelines for stroke care, but has only partially been implemented in Sweden. Following stroke, fatigue is a common consequence that often becomes more evident when the patient comes home. Currently, there is insufficient evidence about how to measure, treat and handle post-stroke fatigue. The overall aim of this thesis was to evaluate and implement early supported discharge (ESD) based on stroke patients experience after discharge from the stroke unit and local conditions. The aim was also to evaluate post-stroke fatigue with a potentially valid and reliable scale and finally to prepare for a study to evaluate cardiorespiratory training as a part of ESD service for patients with post-stroke fatigue.

Methods In paper I, nine strategically chosen patients were interviewed of their experience of falling ill, the hospital stay, discharge, contact with health care after discharge and their request of support. Papers II-III describe and evaluate the development, content, implementation and effects of a locally adopted method for early supported discharge (Umeå Stroke Center ESD) in modern stroke care. Paper II included 153 consecutive patients and paper III, 30 232 patients with first-ever stroke registered in the Riksstroke registry in Sweden. Paper II evaluated number of patients/year, clinical and functional health status, satisfaction in relation to needs, accidental falls/other injuries and resources with the result summarized in a value compass. The implementation process was evaluated retrospectively by means of Consolidated Framework for Implementation (CFIR). Paper III evaluated patient reported outcome measurements (PROMs) at 3 months. The primary outcome in paper III was satisfaction with the rehabilitation after discharge. Secondary outcomes were information about stroke provided, tiredness/fatigue, pain, dysthymia/depression, general health status and dependence in activities of daily living (mobility, toilet hygiene and dressing). Multivariable logistic regression models for each PROM was used to analyze associations between PROMs and ESD/no ESD. In Paper IV, the Fatigue Assessment scale (FAS) was translated into Swedish and evaluated regarding psychometric properties when self-administered by persons with mild to moderate stroke. 72 consecutively patients selected from the stroke unit admission register received a letter including three questionnaires: the FAS, the Short Form Health Survey (SF-36) subscale for

vitality and the Geriatric Depression Scale GDS-15. A second letter with FAS was sent within 2 weeks, for re-test evaluation. Paper V is a study protocol for a planned randomized controlled trial (RCT) of 50 consecutive stroke patients will who receive stroke unit care followed by ESD-service at Umeå Stroke Center, University Hospital, Umeå, Sweden. Paper V will investigate if a structured cardiorespiratory interval training program (CITP) added to the ESD-service may result in relieved post-stroke fatigue and increased oxygen uptake.

Results The interviews in Paper I revealed three main categories with subcategories: "Responsible and implicated", "Depersonalized object for caring measures" and "The striving for repersonalization and autonomy". The findings indicate that coming home gave the informants' important insights and understanding of the stroke, its consequences and was also an important factor for the recovery. Paper II-III showed that it is possible to develop and implement an adapted ESD service for stroke patients based on the patients' experiences and requests, evidence-based recommendations and local conditions. The ESD service reduced dependence of activity, increased mobility with seemingly no increased risk of accidental falls or other injuries. The patient satisfaction in relation to needs regarding the ESD was high. Paper III showed that patients that received ESD were more satisfied with rehabilitation after discharge, had less need for assistance with ADL and less dysthymia/depression compared to patients that did not receive ESD. Study IV showed that the Swedish FAS used at home as a self-administered questionnaire is a reliable and valid questionnaire for measuring fatigue in persons with mild to moderate stroke. The internal consistency was good, the agreement between the test and retest reliability for individual items (weighted kappa) was for the majority of items good or moderate. The relative reliability for total scores was good and the absolute reliability was 9 points. The Swedish FAS had no floor nor ceiling effects and correlated both with the SF-36, subscale for vitality and the GDS-15 indicating convergent construct validity, but not divergent construct validity.

Conclusion It is possible to develop and implement ESD care for stroke patients based on patients' experience and needs, evidence-based principles and local conditions. Early supported discharge (ESD) in the setting of modern stroke unit care appears to have positive effects on rehabilitation in the subacute phase. The Swedish FAS used at home as a self-administered questionnaire is reliable and valid for measuring fatigue in persons with mild to moderate stroke.

Abbreviations

ADL	Activities in daily living
AIS	Abbreviated Injury Scale
BDI	Beck Depression Inventory
CABG	Coronary artery by pass graft
CFIR	Consolidated Framework for Implementation
CI	Confidence Interval
CITP	Cardiorespiratory interval training program
CPET	Incremental cardiopulmonary exercise test
ESD	Early supported discharge
FAS	Fatigue Assessment Scale
FIS	Fatigue Impact Scale
FSS	Fatigue Severity Scale
GDS-15	Geriatric Depression Scale
HR peak	Maximal Heart Rate
$ICC_{3,1}$	Intraclass Correlation Coefficient
k_w	Fleiss-Cohen weighted kappa
LISA	Longitudinal Integration Database for Health Insurance and Labor Market Studies
MAIS	Maximal Abbreviated Injury Scale
NIHSS	The NIH Stroke Scale
MMSE	Mini Mental State Examination
mRS	Modified Rankin Scale
OR	Odds Ratio
PREM	Patient reported experience measurement
PROM	Patient-reported outcome measurement
RCT	Randomized control trial
RLS85	Reactive Level Scale
RMI	Rivermead Mobility Index
RPE	Rate of Perceived Exertion
SAS	Statistical Analysis System
SD	Standard Deviation
S-FAS	Swedish Fatigue Assessment Scale
SF-36	The Short Form Health Survey
S_w	Within-subject standard deviation
TIA	Transient Ischemic Attack
VAS	Visual Analogue Scale
Vo_2	Peak oxygen consumption

Sammanfattning på svenska

Stroke är ett samlingsnamn för hjärnskador som orsakas av en propp eller blödning i hjärnan. Varje år insjuknar ca 25 000 personer i stroke i Sverige. De flesta (80%) är över 65 år. Personer som vårdas efter en stroke behöver fler vårddagar än andra diagnosgrupper och stroke är den vanligaste orsaken till funktionshinder hos vuxna. Vården av stroke patienter har utvecklats och idag behandlas de flesta patienter på en specialiserad strokeenhet. Efter behandling på strokeenhet är tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö (In english early supported discharge, ESD) ett effektivt sätt att förbättra resultat och kvalitet på rehabilitering för personer med lätta eller medelsvåra funktionshinder efter stroke. Metoden för tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö rekommenderas i Socialstyrelsens riktlinjer för strokevård men metoden är idag bara delvis införd i svensk strokevård. Vid införandet av en metod behöver metoden ofta anpassas till lokala förhållanden för den aktuella orten. Hjärntrötthet (fatigue) är en vanlig konsekvens efter stroke som ofta blir mer påtaglig när en person kommer hem och ska klara av sina vardagliga aktiviteter. I dag finns det ingen behandling vid hjärntrötthet men fysisk aktivitet och träning har föreslagits som en möjlig behandling. Ökad kondition genom träning kan eventuellt förbättra en persons möjlighet att orka klara av sin vardag. Det övergripande syftet med denna avhandling var att lokalt anpassa, implementera och utvärdera tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö vid universitetssjukhuset i Umeå. Anpassningen skulle baseras på gällande forskning och personers erfarenheter av att bli vårdade, skrivas ut och komma hem efter stroke. Syftet var också att utvärdera självskattad hjärntrötthet i hemmiljö med en valid (förmåga att mäta vad den avser att mäta) och reliabel (tillförlitlighet) hjärntrötthetsskala och slutligen förbereda för en studie som utvärderar om konditionsträning utfört i hemmiljö kan minska hjärntrötthet efter stroke.

Avhandlingen innehåller fem delarbeten: I det första delarbetetet intervjuades 9 personer som drabbats av stroke kring deras erfarenheter av att bli sjuka, bli vårdade, skrivas ut och komma hem efter stroke. I delarbete II-III beskrivs och utvärderas innehåll, införande och effekten av en lokalt anpassad modell för tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö (Umeå Strokecenter hemrehab). Delarbete II omfattar 153 personer som drabbats av stroke och delarbete III, 30 232 personer med stroke som registrerats i det svenska kvalitetsregistret för strokevård, Riksstroke. Delarbete II utvärderade antal patienter/år, vårdtider, aktiviteter i dagliga livet (ADL) och förflyttningsförmåga, tillfredställelse med vården, fallolyckor och skador samt resursåtgång.

Införandeprocessen utvärderades med ett ramverk för implementering (införande). Delarbete III utvärderade patientrapporterade resultat (In English patient reported outcome measurement PROM) efter 3 månader. Primärt effektmått var självskattad tillfredställelse med rehabilitering efter utskrivning och sekundärt effektmått var självskattad tillfredställelse med den information som getts, självskattad trötthet, självskattad smärta, självskattad nedstämdhet/depression, självskattad generell hälsa och beroende i aktiviteter i vardagliga livet som förflyttning, toalettbesök och påklädning. Deltagarna i delarbete III indelades i två grupper. En grupp hade fått tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö medan den andra inte hade fått det. Jämförelser mellan grupperna gjordes med multivariat logistisk regression. I delarbete IV översattes en hjärntrötthetsskala (Fatigue Assessment Scale, FAS) till svenska som testades vad gäller validitet och reliabilitet på personer som haft stroke för cirka 4 månader sedan. 72 personer fick den svenska versionen av hjärntrötthetsskalan (S-FAS) hemskickade tillsammans med två andra frågeformulär som användes för validering. Deltagarna fick själva fylla i hjärntrötthetskalan och andra skalor och skicka dem tillbaka. Deltagarna fick efter ca två veckor ett nytt brev med samma hjärntrötthetsskala för att undersöka reliabilitet. Delarbete V omfattar ett studieprotokoll som beskriver planering och genomförandet av en randomiserad kontrollerad studie (50 deltagare) som ska undersökas om konditionsträning utfört i hemmiljö kan minska hjärntrötthet efter stroke.

Analysen av intervjuerna i delarbete I, kom fram till tre huvudkategorier med underkategorier: “ansvarsfull och delaktig”, “opersonligt föremål för vårdens åtgärder” och “strävan efter repersonalisering och självständighet”. Att få komma hem var enligt de intervjuade en viktig faktor för återhämtningen efter stroke. Att få komma hem medförde också en ökad insikt kring sjukdommen och dess konsekvenser. Delarbete II och III visade att det är möjligt att utveckla och införa en lokalt anpassad metod för tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö (Umeå Stroke Center hemrehab) som baseras på gällande forskning och personers erfarenheter av att bli vårdade, skrivas ut och komma hem efter stroke. Resultatet visade att Umeå Stroke Centers hemrehab minskade beroendet i aktiviteter i dagliga livet och ökade förflyttningsförmågan utan ökad risk för fallolyckor och skador. Personerna var också nöjda/tillfredsställda med den vård de erhållit. Delarbete III visade att personer som fått tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö var mer tillfredsställda med rehabilitering efter utskrivning, var mindre beroende i aktiviteter i dagliga livet och var mindre nedstämda/deprimerade jämfört med personer som inte fått tidigarelagd

koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö. Delarbete IV visade att den svenska hjärntrötthetsskalan var valid och reliabel för att i hemmiljö utvärdera självskattad hjärntrötthet efter lätt till medelsvårt funktionshinder efter stroke. Resultatet visade också att det behövs 9 poängs skillnad för att vara säker (95%) på att skillnaden är en sann skillnad i hjärntrötthet hos en enskild person.

Sammanfattningsvis visar den här avhandlingen det är möjligt att utveckla och införa en lokalt anpassad metod för tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö (Umeå Stroke Center hemrehab) baseras på gällande forskning och personers erfarenheter av att bli vårdade, skrivas ut och komma hem efter stroke. Tidigarelagd koordinerad utskrivning från sjukhus och rehabilitering i hemmiljö verkar ha en positiv effekt på rehabiliteringsresultatet. Den svenska hjärntrötthetsskalan (S-FAS) är en valid och reliabel skala för att i hemmiljö mäta självskattad hjärntrötthet efter lätt till medelsvårt funktionshinder efter stroke stroke.

Original papers

This thesis is based on the following papers

I. "If only I manage to get home I`ll get better" – interviews withstroke patients after emergency stay in hospital on their experience and needs. Olofsson A*, Andersson SO, Carlberg B. Clinical Rehabilitation 2005;19:433-440 *Maiden name for Anna Bråndal

II. Stroke unit at home: A prospective observational implementation study for early supported discharge from the hospital. Bråndal A, Wester P. International Journal of Physical Medicine and Rehabilitation 2013;1:170. Doi: 10.4172/2329-9096.1000170

III. Effect of early supported discharge after stroke on patient reported outcome – observational study from the Swedish Riksstroke registry. Bråndal A, Eriksson M, Glader E-L, Wester P. Manuscript.

IV. Reliability and validity of the Swedish Fatigue Assessment Scale when self-administered by persons with mild to moderate stroke. Bråndal A, Erisson M, Wester P, Lundin-Olsson L. Topics in Stroke Rehabilitation 2016;23:90.

V. Does a cardiorespiratory interval training program at home improve post-stroke fatigue? Study protocol of a randomized controlled trial. Bråndal A, Glader E-L, Lundin-Olsson L, Wester P. Manuscript.

Preface

My interest in the home environment as an arena for rehabilitation started in the mid-90s. In my clinical practice as a physiotherapist in a stroke unit, it was difficult to create a stimulating exercise environment. Patients often told me that the home environment was different, e.g., stairs and bathrooms. This could sometimes lead to difficulty in motivating the patients. I started to think about transfer effects. Would the outcome improve if the patients had the opportunity to practice in their own home?

In 1995 I had the opportunity to work in a home rehabilitation project with stroke patients called a “stroke rehab chain”. During this project, we went on a field trip to Stockholm where we visited the Östermalm home rehabilitation team and the early supported discharge (ESD) team in southwest Stockholm. These two teams were pioneers in the field of home rehabilitation or ESD and it was inspiring to visit them. Back home, we were not met with enthusiasm, and it took until 2004 when the University Hospital of Umeå was interested in setting up an ESD-team.

So finally, in 2005, I got the opportunity to be part of the development of our locally adapted ESD team. During my work with the ESD team, I was met with new challenges. In the home environment, the patients fatigue became more prominent. I started to reflect on whether and how it is possible to treat fatigue.

Introduction

Stroke is a leading cause of death and disability and a major health problem worldwide. Stroke can affect motor, sensory, language, perceptual and cognitive functions, leading to various consequences for the individual, their family, and society in general (1, 2). This thesis focuses on a method for care and rehabilitation after stroke, i.e., early supported discharge (ESD) and post-stroke fatigue. Post-stroke fatigue is a common and disabling consequence of stroke that becomes more evident when the person is able to cope with their everyday life.

Stroke

Stroke is a general term used for brain injury caused by a disruption of blood flow to the brain. Stroke includes brain infarction (~85%), intracerebral hemorrhage (~10%) and subarachnoid hemorrhage (~5%). Stroke affects men and women approximately equally in total and can occur in all ages. However, the risk of stroke increases with age (3, 4). Stroke is the third most common cause of death in Western countries (5). In Sweden, approximately 25 000 persons suffer from acute stroke each year, and the majority of these are over 65 years of age (4). The treatment of stroke consumes approximately 5% of health service resources and stroke survivors require the most hospital days. The total cost of stroke in Sweden has been estimated to be 12.3 billion SEK (1.5 billion euro) (6) per year.

Stroke care and treatment

The management of acute stroke has developed over the last decade and treatment currently comprises several parts: hyper-acute stroke therapies (thrombolysis, thrombectomy), early carotid interventions, treatment of risk factors (secondary prevention), treatment of complications, nursing care, and rehabilitation (7, 8, 9). The essential principle in rehabilitation following stroke is a functional approach targeting specific activities (task-specific training) such as walking, activities of daily living (ADLs), enough frequency and intensity, and start of rehabilitation early after stroke onset (10). An important factor for the development of stroke care is the establishment of a specialized stroke unit. The stroke unit has been shown to be an effective way to improve the quality of care following stroke. Research has established that stroke units reduce death and disability and improves post-stroke outcome (11). In Sweden, more than 90% of stroke patients are cared for at a stroke unit (4). The stroke unit can initially satisfy the medical, nursing, rehabilitation and psychosocial needs of patients and their families.

However, at the hospital it is difficult to anticipate and address the patient´s needs after discharge and in the long term.

Early supported discharge (ESD)

In the late 1990s, an alternative method was developed to take care of patients after acute stroke. Stroke patients were offered ESD with rehabilitation at home (12, 13). Research has determined that ESD can reduce the length of hospital stay, long-term dependency, and admission to institutional care with no apparent adverse impact on patients or carers. Beneficial effects of ESD have also been described in long-term follow-ups. Extended ADLs, resource use, perceived health status, and the patient's chances of living at home with improved function were more favorable after ESD than after conventional care 5 years after stroke (14, 15, 16, 17). ESD has mainly been investigated in select groups of mild to moderate stroke patients (12, 13).

Important key elements for effective ESD have been identified. For example, a multidisciplinary team with appropriate resources and experience in stroke rehabilitation should provide the ESD service. The ESD team should have regular team meetings and continuously evaluate changes in outcomes using standardized measurements. The ESD assignment could be to coordinate and plan discharge and provide continuing rehabilitation at home for individuals with mild to moderate stroke (18). There are two different types of ESD service depending on the degree of involvement of the ESD team in the post-discharge management. The ESD team can either plan and coordinate the discharge and perform rehabilitation at home, or only plan and coordinate the discharge (12, 13).

ESD is planned and carried out in agreement with the patient and their family. The amount, duration, and intensity of rehabilitation should be determined by each patient's goals (12, 13, 19). The choice of training activities may vary but is often focused on ADLs and mobility. Examples of ADLs are activities in eating, toileting, dressing, bathing, cooking, cleaning, grocery shopping and mobility, such as transfer indoors and outdoors, stair climbing, and public transportation (13). The ESD team also provides information (e.g., on disease, prognosis, risk factors and medication management), psychological support, and co-operate with other actors that are important to the patient and their family (20).

The patient´s involvement in rehabilitation is probably one of the reasons that ESD is successful. In the home environment, it is easier for the patient to feel involved, motivated, and set realistic goals for their rehabilitation (21-

23). Another reason that the ESD has been successful is that the ESD team members work together and can complement each other, It allowing the ESD team to support the patient's entire situation (22, 24).

The experience of early discharge and returning home following stroke has been highlighted in a systematic review (25), which revealed that the process of change and disruption of life becomes more obvious once the patient is home. The authors emphasized the importance of exploring the experience further to achieve greater understanding. Subsequently, studies have investigated patients' experiences with the homecoming and home rehabilitation in the context of ESD (23, 26, 27). These studies indicate that patients are positive about returning home and express great satisfaction at undergoing rehabilitation within the home environment, where the patients felt they were better able to perform ADLs and meaningfully participate in life roles (23). Patients and their families appreciate skilled professionals who also show an understanding of their situation (27).

The patients and their families also highlighted areas of ESD that can be improved. Patients and their carers reported being inadequately informed of causes and prognosis of stroke, secondary prevention, and informal support (27). They asked for more stroke-related information, emotional and psychological support, contact with their general practitioner, physical training, and a more flexible service suited to their needs (23, 26, 27). They also argued the need for support and training for carers in skills essential for the day-to-day management of stroke patients (23).

Today, the ESD is highly variable among different stroke organizations and local adaptation of the method is often necessary to enable implementation. Criticism has been raised that most of the randomized controlled trials (RCTs) on ESD services were published more than 10 years ago (28). The very few up-date studies have found reduced length of stay and equivalent or better outcomes for stroke patients and their families as previously shown in randomized control trials (29, 30).

Despite recommendations in the national guidelines for stroke care (7), the proportion of stroke patients receiving ESD in Sweden varies. Riksstroke, the Swedish Stroke Register, reported in 2014 (2) that the proportion of stroke patients stating that they received ESD varied between 4% and 32%. This wide variety across the country has been confirmed in a recent practice survey (13). Thus, there is a gap between what is recommended in the national guidelines and the stroke care that can be offered. Reasonably, more stroke survivors should be eligible for ESD in Sweden.

Post-stroke fatigue

Returning home is an important step for stroke survivors in understanding the consequences of their disease (31, 32). Fatigue is common after stroke, can be long lasting, and can hinder participation in ADL (33-37). Post-stroke fatigue is a subjective experience with no widely accepted definition (38), but is often defined as a feeling of early exhaustion or tiredness, occurring during mental and/or physical activities with a feeling of weariness, lack of energy, and aversion to effort (34, 35). Post-stroke fatigue affects about 23-75% of all stroke survivors and is also common among patients with minor stroke (33, 35, 39-41). The way of measuring fatigue can be one factor that explains the large variation of the results. Post-stroke fatigue has been graded as one of the worst self-reported symptoms in stroke survivors with mild and non-disabling symptoms (35, 40, 41). There is uncertainty surrounding the cause of post-stroke fatigue; it is considered to be multidimensional and can involve physiological, social, emotional, behavioral and cognitive processes. Post-stroke fatigue has been associated with poor neurological recovery, higher degree of dependency, institutionalization, mortality, and depression (35-37, 43-46).

Measurement of post-stroke fatigue

Different approaches can be used to evaluate post-stroke fatigue. The most common method is to use a scale. A fatigue scale includes questions about different aspects of fatigue and the subject is asked to estimate its presence and/or severity of fatigue. Another method is to use a case definition of post-stroke fatigue (47) or a single question about fatigue (43). Although different measurements have been developed to evaluate fatigue, it is difficult to find instruments that capture its complexity. In addition, many of the scales used to evaluate post-stroke fatigue were developed for other conditions and their validity and reliability in stroke is unknown (48). Validity reflects the degree to which a scale measures what it is supposed to measures, in this case, fatigue (49). Reliability refers to reproducibility, i.e., repeated measurements of individual performance are stable over time. Test-retest reliability is most commonly determined from measurements of the same subject on two occasions (49).

Examples of scales used to evaluate post-stroke fatigue are the Fatigue Assessment scale (FAS) (48, 50), the Fatigue Impact Scale (FIS) (33, 50), the Checklist of Individual Strength (35), the Visual Analogue Scale (VAS) (51, 52), the Multidimensional Fatigue Symptom Inventory (53) and the Fatigue Severity Scale (FSS) (33, 51-55). An evaluation of four fatigue scales in stroke patients showed that all of the scales were valid and feasible, but the FAS had

the best test-retest reliability (48). Another report also found high test-retest reliability of FAS in stroke patients (50). The FAS is considered to explore multiple aspects of fatigue that can be useful in assessing the multi-faceted nature of post-stroke fatigue (34).

Treatment of post-stroke fatigue

Although post-stroke fatigue is common, there is insufficient evidence of how to treat and handle post-stroke fatigue (34, 56-59). Because post-stroke fatigue is considered to be multidimensional, different interventions may be appropriate. Pharmacological treatments have focused on medications with mood-enhancing medications and central stimulant drugs. Non-pharmacological treatments have included mapping of activity patterns and triggers, adapting activities, and information on relaxation and stress reduction techniques and healthy sleep patterns (33, 56, 58). Another intervention strategy is to treat underlying causes of fatigue, such as sleep apnea, depression, dehydration, anemia, malnutrition, and pain (33, 35, 56). Physical activity and exercise has been suggested as a possible intervention, because it is thought to accelerate the recovery of the brain (60, 61) and that an increased cardiorespiratory fitness improves people's ability to cope with everyday life (35, 61, 62). A previous study reported that cognitive behavioral therapy plus graded activity training is more effective in reducing post stroke fatigue than cognitive behavioral therapy alone. This trial did not determine whether the reduction of fatigue was a result of the physical training alone or a combination of the interventions (63).

Physical activity and cardiorespiratory training after stroke

Physical activity describes all bodily movement produced by the contraction of skeletal muscle and that increases energy expenditure. This comprises all muscular work required to maintain posture, walk, perform daily activities and perform occupational, leisure, and sporting activities (64).

Physical fitness is a set of features that a person has or achieves that relates to the ability to perform physical activity. Physical fitness includes the following key components: cardiorespiratory fitness, muscular strength, and body composition. Cardiorespiratory fitness is an individuals' ability to perform physical activity for an extended period. It depends on the central capacity of the circulatory and respiratory systems to supply oxygen (64), and the peripheral capacity of the skeletal muscle to utilize oxygen (65).

Spontaneous physical activity and cardiorespiratory fitness is lower in stroke survivors than in healthy subjects (66-69). The peak oxygen consumption

(Vo_2) is a common measure of cardiorespiratory fitness (70). After stroke, the Vo_2 often decreases below the level required to perform most everyday tasks (71). The reduction in physical activity after stroke is not only a reduction of time spent being active, as stroke survivors also carry out activities at a slower speed (71).

In recent years, cardiorespiratory training has been highlighted as an important component to add to rehabilitation after stroke (69, 70, 72-74). Cardiorespiratory training has been suggested to be important to include in in already existing rehabilitation programs (75). Today, there is evidence that cardiorespiratory training can improve cardiorespiratory fitness in people with mild to moderate disability after stroke with a relatively low risk of cardiac complications. The recommendations are 20-60 min, 3-7 days/week at 50-80% of the maximum heart rate (73). Cardiorespiratory training designed as interval training has been shown to improve cardiorespiratory fitness in different patient groups, including stroke (75-80). Studies have also shown that cardiorespiratory training can improve the speed of information processing, motor learning, memory, and motor function and reduce depression after stroke (81, 82). Studies examining cardiorespiratory training have used different forms of ergometers (e.g., treadmill, cycling, rowing, Kinetron) or modes of activity, such as walking or stair climbing (70, 75).

Implementation

Implementation science is defined as the scientific investigation of methods to promote the systematic uptake of research and other evidence-based practice (EBP) into routine practice to improve the quality and effectiveness of health services and care. Adaptation of methods is often necessary to enable implementation (83). Implementation science has had trouble to identifying specific factors for successful implementation. These difficulties are associated with the outcomes of the implementation process usually depending on changes in complex interactions between many different factors. In implementation research, categorizing possible determinants of the implementation process. Determinants (explanatory factors or independent variables) include both hindering and facilitating factors that may affect the implementation process (84). Different theories, models, and frameworks can be used in implementation science. The aims of using theories, models, or frameworks is to describe and/or guide the process of translating research into practice, understand and/or explain what influences implementation outcomes, and evaluate implementation (85).

The International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) (86) is a classification of health and disability from body, individual, and societal perspectives. The overall aim of the ICF classification is to provide a standardized language and framework for the description and definition of components of health, health-related states and well-being. The ICF contains of two parts, each with two components: The first part includes body functions/Structures and activities/participation. Since individual functioning and disability occurs in a context, the second part includes environmental factors and personal factors. The ICF defines participation as involvement in a life situation and environmental factors as the physical, social, and attitudinal environment in which people live and conduct their lives. All the components of the ICF interact, which means that an individual´s functioning in a specific domain is an interaction between the health condition and contextual factors. The ICF framework will be taken into account in the discussion of the results in this thesis.

Rationale for the thesis

ESD has been shown to be an effective way to improve patient outcomes and the quality of care following stroke. ESD is recommended in the national and international guidelines for stroke care but has only been partially been implemented in Sweden and elsewhere. Thus, a gap exists between recommendations and the stroke care that can be offered. Furthermore, only a few studies have investigated ESD services in regular practice. Evidence of the efficacy and safety of ESD in the today's stroke care with shorter hospital stays and access to hyper-acute therapies is lacking. To enable implementation, adaptation of the method is often necessary. A deeper understanding of the patient's experience with discharge can further develop the ESD services.

Post-stroke fatigue often becomes more evident and disabling when the patient returns home and starts coping with their daily life. Even though post-stroke fatigue is common and negatively influences recovery, there are no guidelines for its management and treatment. Physical activity and training has been suggested as a possible intervention. Cardiorespiratory training in the patient´s home may be preferred for patients with post-stroke fatigue when exhausting travels is avoided. Cardiorespiratory training has not yet been evaluated as a treatment for post-stroke fatigue. Therefore, it is unclear if cardiorespiratory training can relieve post-stroke fatigue or whether it is feasible and safe to perform cardiorespiratory training in the patient's home as a part of the ESD intervention.

When evaluating treatments, such as cardiorespiratory training, it is important to use measurements that meet the requirements for validity and reliability. There is currently no valid and reliable post-stroke fatigue scale available in Swedish. The FAS has shown promising results regarding psychometric properties when used in stroke populations. The FAS has not been translated into Swedish.

The aims of the thesis

The overall aim of this thesis was to evaluate and implement ESD based on stroke patients' experiences after discharge from the stroke unit and local conditions. Another aim was to evaluate post-stroke fatigue using a valid and reliable scale and to prepare for a study to evaluate cardiorespiratory training as a part of the ESD service for patients with post-stroke fatigue.

The specific aims were to:

- Explore patients' experiences with falling ill, the hospital stay, discharge, contact with health care after discharge, and their request of support.

- Describe and evaluate the development, content, implementation and results of a locally adopted method for ESD and stroke-home rehabilitation (Umeå Stroke Center ESD).

- Evaluate patient-reported outcomes (PROMs) in stroke patients receiving modern stroke unit care and ESD according to the Umeå Stroke Center model and patients without ESD.

- Translate and examine the internal consistency, test-retest reliability, floor/ceiling effects, and construct validity of the Swedish Fatigue Assessment Scale (S-FAS), when self-administered by persons with mild to moderate stroke.

- Formulate a study protocol for a study investigating whether a structured cardiorespiratory interval training program (CITP) added to the ESD may result in relieved post-stroke fatigue and increased oxygen uptake.

Materials and methods

This thesis encompasses four papers and a study protocol. A timeline for the papers are presented in Figure 1. An overview of the study designs, population, and inclusion and exclusion criteria are provided in Tables 1 and 2.

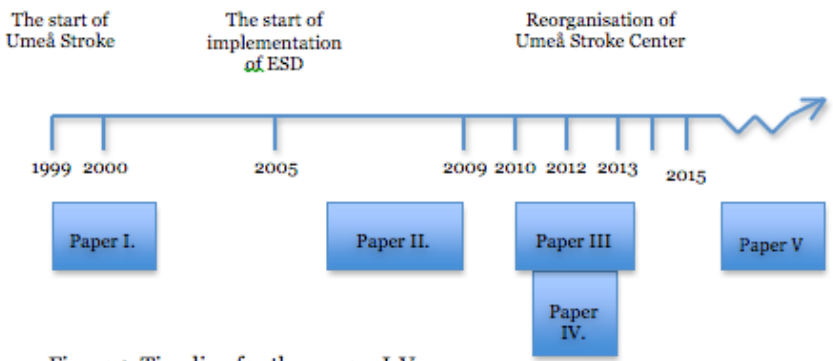

Figure 1. Timeline for the papers I-V

Setting

The setting for these studies was the patients' homes. The organization of the stroke care and rehabilitation at the university hospital in Umeå has changed during the study period (2002-2016).

In the early 2000s, the stroke care in Umeå was organized at three units: a medical medicine ward, a geriatric ward, and a neurorehabilitation ward. At stroke onset, the patient was admitted to the stroke unit in the Department of Internal Medicine. The stroke unit was responsible for acute care and rehabilitation up to a maximum of 4 weeks. If needed, the patient was then transferred to in-patient rehabilitation at the geriatric ward or the neurorehabilitation ward (age ≤ 65 year). For patients who were discharged directly to their home, there were limited opportunities for rehabilitation and follow-up in primary care. Some of these patients could, after a waiting period be offered outpatient day hospital care/rehabilitation (geriatric outpatient rehabilitation or work-related rehabilitation).

In September 2004, the board of Västerbottens County Council in Northern Sweden gave stroke team members the commission to develop and implement ESD services for stroke patients at the university hospital in

Umeå. Development and implementation started in January 2005. Initially, the ESD team was organized as a part of the Department of Geriatric Medicine. The aim was to offer ESD and home rehabilitation to patients regardless of age.

In May 2009 there was a reorganization of stroke care at the university hospital in Umeå. The stroke unit, Umeå Stroke Center, became responsible for acute care, nursing, rehabilitation and outpatient medical follow-up and ESD services with an unbroken care chain. During the reorganization the ESD service expanded to two teams with an increased catchment area (100 km) and mandate to offer ESD service to patients with somewhat more severe stroke.

Table 1. Overview of study design and study population in paper I-V

	Paper I	**Paper II**	**Paper III**	**Paper IV**	**Paper V**
Study design	Qualitative interview	Prospective observational Implementation	Register based Cross sectional	Prospective Validity and reliability	Study protocol RCT
Setting	Home	Home	Home	Home	Home
Patients (n)	(n = 9)	(n =153)	(n=1495)	(n =72)	(n = 25)
Sex n (%)					
M	4(44)	69(45)	829(55,5)	49(69)	
F	5(55)	84 (55)	666(44,5)	22(31)	
Age mean	72	74	73	68	
Control (n)			(n = 28737)		(n= 25)
Sex n (%)					
M			15491 (53,8)		
F			13276(46,2)		
Age mean			74		

Table 2. An overview of inclusion- and exclusion criteria in paper I-V.

Paper	Inclusions criteria	Exclusions criteria
I	Ischemic or hemorrhagic stroke Stroke four month ago. Strategically chosen (sex, age, civil status and symptoms). Discharged to their own home. Resident in Umeå. Acceptable communication capacity	
II	Ischemic or hemorrhagic acute stroke. Medical stability. Continued need for rehabilitation. Living in Umeå or nearby surrounding areas Verbal consent from the patient and family	Severe stroke (mRS >3.) Serious co-morbidity. Severe cognitive dysfunction. Drug abuse. Patients living far away from the hospital Lived in residential care facilities.
III	Ischemic or hemorrhagic acute stroke. Mild to moderate severity at admission (RLS85 1-3) Living at home. ADL independency at stroke onset. Recorded in Rikstroke.	Lived in residential care facilities. Severe stroke (RLS85 ≥4.) Diagnosis of TIA. Diagnosis of recurrent stroke.
IV	Mild to moderate ischemic or haemorrhagic stroke	Lived in residential care facilities. Severe cognitive dysfunktion. Severe stroke (mRS >3).
V	Ischemic or hemorrhagic acute stroke. Post stroke fatigue (S-FAS > 30) Medical stability. Living in Umeå or nearby surrounding areas Be able to sit on a cycle ergometer.	Severe stroke (mRS >3). Unstable pulmonary or cardiac disease. Serious co-morbidity. Severe cognitive dysfunction (MMSE≤20.) Drug abuse. Patients living far away from the hospital. Lived in residential care facilities.

MRS = Modified Rankin scale(87)

TIA = Transient ischemic attack

S-FAS = The Svedish fatigue assessment Scale

RLS85 = Reactive Level Scale (88)

MMSE = Mini Mental State Examination(89)

Interviews with stroke patients on their experiences with hospital stay and discharge (Paper I)

The aim of paper I was to explore patients' experiences with falling ill, hospital stay, discharge, contact with health care after discharge, and their request of support.

Participants, data collection and analysis

The informants were nine patients with stroke who had received care at the stroke unit at Umeå Stroke Center, Umeå University Hospital. The participants were strategically chosen to gain different perspectives. The selection was based on gender, age, civil status, and stroke symptoms (Table 3). The inclusion and exclusion criteria are provided in Table 2.

Table 3. Characteristics of the informants

IP	Gender (m/f)	Age (Years)	Civil status	Earlier illness	Diagnosis	Symptoms on falling ill
1	m	64	husband	Hypertension, TIA, Pain in legs	Intraventricular hemorrhage	Weakness left side, impaired balance
2	f	71	Married	CABG, Angina pectoris	Cerebral hemorrhage	Loss of sensation, weakness left side,
3	f	77	Married	Hypothyroidism, neck problem	Cerebral infarction	Aphasia, neglect, impaired balance
4	f	72	Married	Hypertension, osteoporosis	Lacunar infarction	Loss of sensation left side
5	m	83	Widower	Hypertension, Diabetes, asthma	Cerebral infarction	Paresis left side, neglect
6	f	65	Widow	Neck problem	Cerebral infarction	Weakness left side,
7	m	69	Married	Hypertension, stroke	Cerebral infarction	Aphasia, loss of field of vision
8	m	71	Married	Abdominal aorta aneurysm, back pain	Cerebral infarction	Aphasia, paresis right side
9	f	78	Widow	Diabetes, hypertension stroke, rheumatism	Minor stroke	Paresis right side

TIA = Transient ischemic attack

CABG = coronary artery by pass graft

One of the authors (AB) conducted the interviews in the informants' homes. The interviews were tape recorded and transcribed verbatim by the author. An interview template (Appendix I) was used with questions about falling ill, the patient´s stay in the hospital, admission, his or her experience of returning home, follow-up appointments, and rehabilitation after the acute stay in the hospital. The authors conducted the analysis both individually and jointly. The interviews were analyzed using a procedure described by Miles and Huberman (90). This procedure is appropriate for illuminating similarities and differences within data material. The text was analyzed in the following steps:

1) The interviews were read several times to get a sense of the content in its entirety.
2) One set of questions was analyzed at a time. Similarities and differences in the patients' stories were looked for and noted. Meaning units (text segments that convey interesting information in relation to the research question) were derived from the text (data reduction), condensed, and labeled with a code capturing the key concept of the text.
3) To promote further penetration and understanding, the codes were grouped into subcategories and categories. The categories were created from the pattern of similarities and differences seen in the material.
4) Citations were linked to subcategories and categories.

The analysis started directly after the first interview and the results from the earlier interviews had on impact on the subsequent interviews. This approach made it possible to judge when new interviews did not provide new information for the analysis (i.e., "theoretical saturation" was reached) (91).

Permission to carry out this research was given by the medically responsible doctor at the stroke unit, Umeå, University Hospital and the Regional Ethics Committee at Umeå University (Dnr 02-146).

The content, implementation, and effects of Umeå Stroke Center´s ESD (Papers II- III)

Papers II-III describe and evaluate the development, content, implementation and effects of a locally adopted method for ESD (Umeå Stroke Center ESD) (92) in modern stroke care. The hypothesis had four parts: (I) ESD according to the Umeå Stroke Center model is feasible in a selected stroke population; (II) Umeå Stroke Center ESD is associated with favorable clinical outcome; and (III) Umeå Stroke Center ESD is not associated with increased risk of accidental falls and other injuries; and (IV) patients receiving ESD exhibit improvements in PROMs. The study was approved by the Regional Ethical Review Board in Umeå, Sweden (Dnr 2012-179-32M, 2014-273-32M).

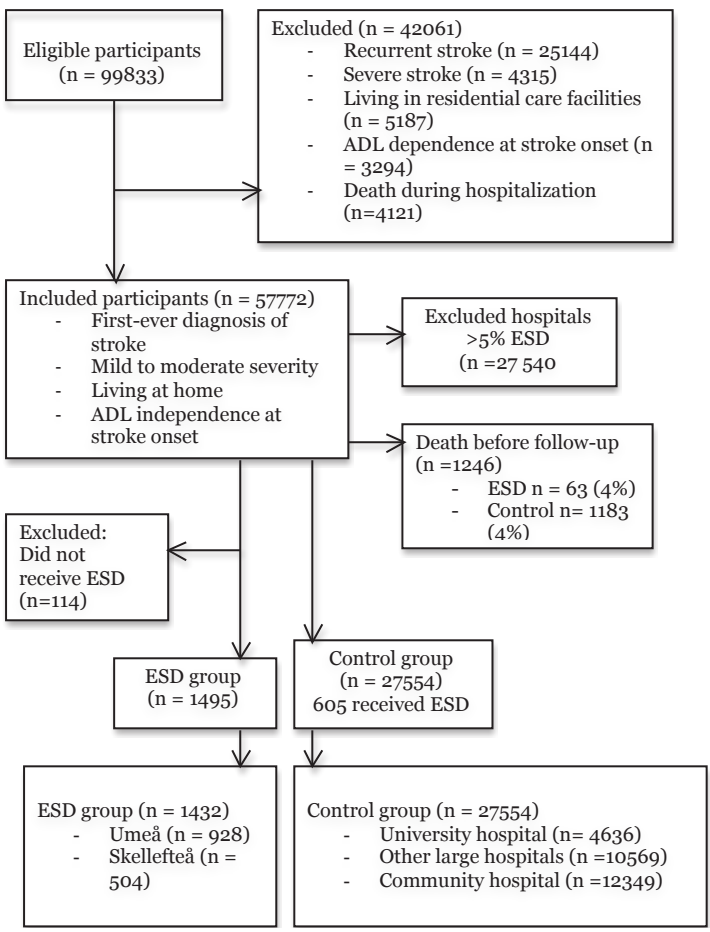

Figure 2. Flow chart of the inclusion procedure paper III.

Participants

Paper II included 185 consecutive patients who received stroke unit care and ESD and home rehabilitation. The participants were enrolled from 1 January 2008 to 17 May 2009. The physician at the stroke unit determined if the patient was suitable for ESD. The patients and their families were informed about the ESD service and provided verbal consent before discharge. Paper II was approved by the Regional Ethical Review Board in Umeå, Sweden (Dnr 2012-64-31M).

Paper III included patients registered in Riksstroke (93) with a first-ever diagnosis of acute stroke between January 2010 and 31 December 2013. The patients were divided into an ESD group (intervention group) and a control group. The ESD group consisted of 1495 consecutive stroke patients who received stroke unit care followed by ESD at Umeå Stroke Center and Skellefteå Hospital. The control group consisted of 28 737 consecutive stroke patients who received acute stroke care at stroke units with a low (< 5% of all stroke patients) proportion of patients referred to ESD. For further analysis the ESD and the control groups were also divided into subgroups dependent on the type of hospital (university hospital or small hospital) (Figure 2) (94). Paper III was approved by the Regional Ethical Review Board in Umeå, Sweden (Dnr 2012-179-32M, 2014-273-32M). The inclusion and exclusion criteria for papers II and III are presented in Table 2.

Umeå Stroke Center ESD team and intervention

Umeå Stroke Center ESD team consists of one full-time physiotherapist, one full-time occupational therapist, and a part-time (50%) nurse, part-time (25%) stroke physician and a part-time (50%) social worker. A speech therapist, psychologist and dietician are consulted if necessary. The interdisciplinary ESD team meets daily for coordinating and planning interventions once a week for medical discussions and long-term planning. An important part of the teamwork is that all professionals share their knowledge and are able to work across professional borders to ensure efficient resource utilization.

Prior to hospital discharge, the team at the stroke unit makes a survey of each participant`s home situation, home environment and needs of municipal assistance. If necessary, a home visit is performed before discharge. The patient receives the first visit from the ESD team directly after discharge. The patient´s needs and the team's workload determined which professional(s) performes the first visit. During the first visit, the patient and their family receives information about the ESD service and an individual

rehabilitation plan is designed. The rehabilitation is planned and carried out in agreement with the patient and his/her familiy.

The ESD service is initially performed 5 days per week and successively reduced when the patient becames more independent in his or her daily activities. The amount of rehabilitation, choice of training activities, and duration and intensity of rehabilitation is based on each patient's needs and goals. The intervention consists of task-specific training in the patient's home and neighborhood. The patient and their family are continually informed about the disease, prognosis and risk factors. They were also provided with support and practical advice about how to manage everyday tasks, such as the adaptation and prioritization of activities, post-stroke fatigue, physical activity and medication management. Patients are re-admitted to the in-hospital stroke unit care if the ESD service can not guarantee safe health care and rehabilitation at home.

The ESD team also provides support in contact with the home care service and could offer supervision, instruction and evaluation of the patient's need for assistance in ADLs. The home care service assistes the patient and their family with tasks that they could not handle, such as grocery shopping and cleaning.

Most patients receive support/rehabilitation from a physiotherapist and an occupational therapist. The nurse primarily focus on patients who do not have an established contact with primary care. Patients with established contact with the nurse at primary care continue with such contact upon returning home. The social worker specifically visits patients and/or families with social needs. The stroke physician was frequently consulted by the other team members and occasionally had phone contact with the patient and their family. The stroke physician performs home visits when necessary.

The progress of rehabilitation is assessed continuously using standardized measurements, such as ADL, balance, mobility and arm-hand function. The results are compared with the individuals' goals. The ESD service was completed when the patient's individual goals have been achieved. After completion of ESD, information is transferred in writing (and verbally if needed) to the next step in the chain of care, usually primary health care, municipal home care, or sometimes rehabilitation facilities.

Implementation

In paper II, the implementation was evaluated intwo different ways. Firstly, ESD was evaluated and implemented according to the different phases of improvement (Plan-Do-Study-Act) (95). Secondly, a retrospective analysis was carried out using a determinant framework called the Consolidated Framework for Implementation (CFIR) (96). The CFIR includes five determinants called domains: i) the interventions characteristics (evidence, strength, and quality); ii) inner setting (structural, political, and cultural contexts); iii) outer setting (economic, political, and social context); iv) characteristics of the individual involved (individual knowledge and belief towards changing behavior, self-efficacy to make changes, identification in the organization, personal attributes): and v) the process that implementation accomplished (planning, engaging, executing, reflecting and evaluation).

Outcome measures (paper II)

The Umeå Stroke Center ESD was evaluated using the value compass (97, 98) and by mapping accidental falls and other injuries in persons who received the ESD. The value compass is a method for describing the value of care for a specific patient group in four dimensions: clinical status, functional health status, satisfaction in relation to needs and costs and recourses.

Clinical status
Clinical status was evaluated by number of patients each year, length of stay (minimum, medium, median, maximum) and re-admissions.

Functional health status
Functional health status was evaluated with the ADL-stairs (99) and the Rivermead Mobility Index (RMI) (100-102) because they measure different aspects of functional health status. The ADL-stairs and the RMI were measured at enrollment and discharge from the ESD service.

The ADL-stairs is a development of the Katz ADL index (103), which measures the level of dependence in sex activities (eating, continence, transfer, toileting, bathing and dressing). In the ADL-stairs, four more activities have been added (cooking, public transportation, grocery shopping, and cleaning). At step 0, the person is completely independent and step 10 implies that the individual is dependent on another person for all activities. The ADL-stairs has been tested for reliability and validity (99). The RMI (100-102) measures disability related to body mobility. The RMI measures

performance and includes 15 mobility items, from turning over in bed to running. The items are hierarchically arranged and ordered according to level of difficulty. The scores range from 0 (poor mobility) to 15 (good mobility).

Satisfaction in relation to needs
Satisfaction in relation to needs (patient satisfaction) was measured using an early version of the National Patient Survey developed for patients in Västerbotten County Council (104). The survey comprises four questions: response, information, participation in care and treatment, and availability of care and treatment. Patient satisfaction was measured at discharge from the ESD services.

Costs and resources
An economist at the department calculated the estimated costs of ESD on one occasion during the study period. The total cost includes staff, administrative costs, laboratory, general services, equipment, medical technology, internet, telephone and corporate costs. The resources were recorded as treatment hours for each profession. The costs of health and social care in the community were not calculated.

Accidental falls and other injuries
Accidental falls and other injuries were evaluated by analyzing the Umeå University Hospital injury registry, which records all patients seeking medical attention at the emergency unit because of an injury. The ESD patients were linked to the injury registry through personal identification numbers. The Umeå University Hospital injury registry uses the Abbreviated Injury Scale (AIS) (105) to grade injuries. The AIS is based on injury severity and location, and each individual injury is classified. The Maximal Abbreviated Injury Scale (MAIS) was used to classify injury on a six-point scale ranging from 1 (mild injury) to 6 (maximum, fatal injury).

Outcome measures (paper III)

Data from the Swedish Stroke Register, Riksstroke (93), and the Longitudinal Integration Database for Health Insurance and Labor Market Studies (LISA) were used to respond to the hypothesis that patients receiving ESD exhibit improvements in PROMs. The outcome variables were PROMs from the 3 month Riksstroke follow-up questionnaire. Satisfaction with the rehabilitation after discharge was set as the primary outcome and information about stroke, tiredness/fatigue, pain, dysthymia/depression, general health, and ADL dependence (mobility, toileting and dressing) were secondary outcomes. Further details on the coding of the variables in the

data analysis are described in paper III. Riksstroke was linked to the LISA database through personal identification numbers.

The Swedish Stroke Register, Riksstroke

Riksstroke started in 1994 and currently covers all hospitals (72 hospitals in 2010 and 2013) treating acute stroke patients. The aim of the register is to monitor and support improvements in the quality and implementation of new methods in stroke care in Sweden. In 2010-2013, Riksstroke had an estimated coverage of ~89% of all acute stroke patients treated in Swedish hospitals. Riksstroke includes patients of all ages with ischemic and hemorrhagic stroke, both first-ever and recurrent stroke. The register covers basic patient characteristics including age, gender, living conditions, history of previous stroke, comorbidities, diagnosis, level of consciousness on arrival, pharmaceutical treatment, and complications. Furthermore, the register contains information about the sequences of care, such as the type of stroke care organization and department. The Riksstroke also has a 3-month and a 12-month follow-up questionnaire that describes PROMs and rehabilitation after stroke. According to the Riksstroke annual reports from 2010 to 2013, the estimated coverage for the 3-month follow-up was approximately 88%. The PROM variables have been validated with a generally good acceptance and accurate reliability (4). Baseline variables and the PROMs were collected from Riksstroke.

The Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA)

The LISA at Statistics Sweden includes information on all Swedish citizens from 16 years of age and older. In the database there is information on socioeconomic factors, such as disposable family income, education, and country of birth. Information on education and country of birth was obtained from the LISA.

Translation and evaluation of psychometric properties of the S-FAS (Paper IV)

In paper IV, the FAS (106, 107) was translated into Swedish and evaluated regarding internal consistency, test-retest reliability, floor/ceiling effects and construct validity.

Participants

A total of 72 consecutively patients admitted to the stroke unit at Umeå University Hospital, Sweden were recruited between 1 April 2012 and 31 December 2012. The participants were retrospectively identified approximately 4 months after stroke onset (Figure 3). The inclusion and exclusion criteria are presented in Table 2. The sample size was based on a power analysis calculated prior to the study as described in paper IV.

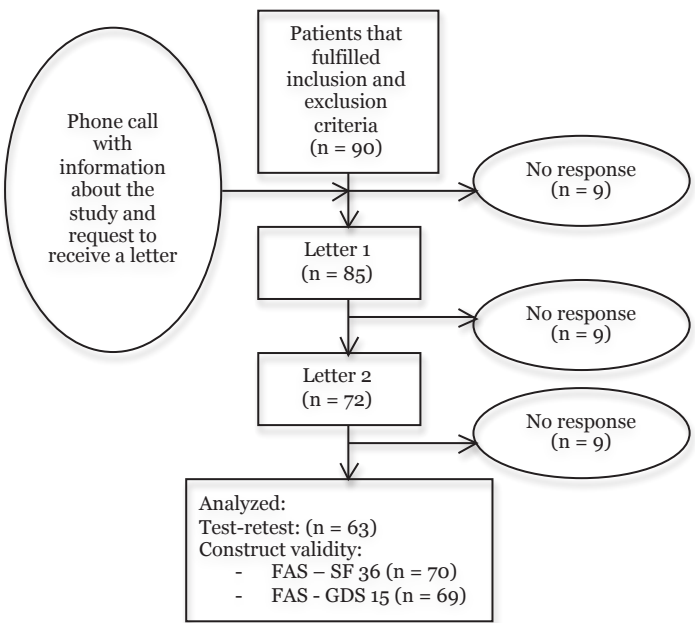

Figure 3. Flow chart for paper IV.

Fatigue Assessment scale (FAS)

The FAS (106, 107) includes 10 self-rated questions that describe how a person generally feels and are scored on a 5-point ordinal rating scale rating from 1 (never) to 5 (always) with a total score between 10 and 50 points. Two items of the FAS require reversed scoring (items 4 and 10). The FAS has shown promising results regarding psychometric properties when used in stroke populations, but the internal consistency has shown varying results and floor and ceiling effects, and the absolute reliability has not been examined (48, 50). The FAS was originally developed in the Netherlands through semantic analysis of four common fatigue scales. The FAS is available in Dutch and English but not in Swedish.

Translation process

The FAS was translated into Swedish according to the guidelines suggested by Sousa (108). The translation was performed in the following steps:

1. Verbal approval from the original developers to translate the FAS into Swedish.

2. Independent translation of the FAS into Swedish by four persons (two pairs) with different backgrounds.

3. Two Swedish versions of the FAS were merged into a new version that incorporated aspects of both translations.

4. The new version was pilot tested in two persons from the target population to determine how well the instructions, questions, and response options were understood.

5. Evaluation of an expert panel to further investigate the content, structure, and relevance. The expert panel was asked to rate the clarity of the instructions and the items and to suggest changes when questions were considered unclear.

6. The author (AB) updated the preliminary version to create a revised Swedish version of the FAS.

7. Back-translation into English by a professional translator.

8. The original developers approved the back-translation of the S-FAS.

Evaluation of psychometric properties

The internal consistency, test-retest reliability, floor/ceiling effects, and construct validity of the S-FAS self-administered by persons with mild to moderate stroke were evaluated. The Short Form Health Survey (SF-36) (109, 110) subscale for vitality and Geriatric Depression Scale (GDS-15) (111, 112) were selected as gold standards to investigate convergent and divergent construct validity. Construct validity was defined as the extent to which the FAS measured the target phenomenon fatigue. Convergent construct validity is the degree to which two or more measurements evaluates the same target phenomenon. Divergent construct validity is when a measurement evaluates related but different phenomena (49).

Our hypothesis was that the S-FAS has a stronger correlation with the SF-36, subscale for vitality than to the GDS-15. The S-FAS was assumed to measure fatigue similar to the SF-36 subscale for vitality. The GDS-15 was assumed to measure symptoms of depression.

The SF-36, subscale for vitality (109, 110) reflects how strong and energetic or tired and worn out a person feels and measures an important aspect of subjective wellbeing. A low score is associated with feelings of general fatigue and exhaustion. The SF-36 focuses on how the person feels currently and how the person has felt for the past 7 days.

The GDS-15 (111, 112) is a screening instrument designed to identify depressive symptoms in elderly persons. The scale comprises 15 questions regarding high and low mood, lack of energy, anxiety, and social withdrawal. The GDS-15 asks how the person feels currently and how the person has felt during the previous week.

The S-FAS was evaluated approximately 4 months after the patient´s stroke to minimize the fatigue level being influenced by spontaneous recovery. Eligible participants received a phone call with information about the study and an invitation to participate (Figure 1). If interested, the patients received a letter that included information about the study, written consent, a stamped response letter, and three questionnaires: the S-FAS, the SF-36 subscale for vitality, and the GDS-15. A second letter with the S-FAS and a stamped response letter were sent when the first letter was returned in order to examine test-retest reliability.

The first letter also included a questionnaire about the participants' functional status in terms of mobility (RMI) (102-104). Mobility was measured with the RMI (100-102), which covers 15 activities, from turning

over in bed to running. RMI has been shown to be valid to use in stroke patients (78). To evaluate the level of consciousness, arm and leg paresis, and language of the NIH Stroke Scale (NIHSS) (113) was used at admission to the stroke unit. The study was approved by the Regional Ethical Review Board in Umeå, Sweden (Dnr 2012-65-31M).

Does a cardiorespiratory interval-training program (CITP) at home improve post-stroke fatigue? (Paper V)

Participants and procedure

Paper V is a study protocol (114) for a planned 1:1 prospective, randomized, open-label trial with blinded evaluators (PROBE-design) (115) of 50 consecutive stroke patients who received stroke unit care followed by ESD at Umeå Stroke Center, University Hospital, Umeå, Sweden. The hypothesis is to determine if structured cardiorespiratory interval training program (CITP) performed in the home environment, result in relieved post-stroke fatigue and improved cardiorespiratory fitness and to explore whether it is feasible and safe for patients with post-stroke fatigue to perform a structured cardiorespiratory interval training program (CITP) in their home environment.

The study has two parts. First, a feasibility study (116) will be conducted in 4-6 participants that received the intervention. With this procedure the set-up of the RCT can be modified slightly. Eligible patients will be examined by a stroke physician 4 (± 2) weeks after discharge from the stroke unit and be included if they fulfill the inclusion criteria (Table 2).

As a part of the ESD service, all patients receives information about post-stroke fatigue, including support and practical advice on how to identify and manage fatigue symptoms in daily tasks, such as the adaptation and prioritization of activities, physical activity and rest. The participants in the intervention group will also receive structured CITP on an ergometer cycle.

All participants will be assessed at inclusion (pre-treatment test) and on two follow-up assessments: immediately after the end of intervention (post-treatment test) and 6 weeks after the end of the intervention (6 weeks follow-up test). All participants will be provided with a home-exercise logbook and asked to continue with their normal community routine and rehabilitation interventions.

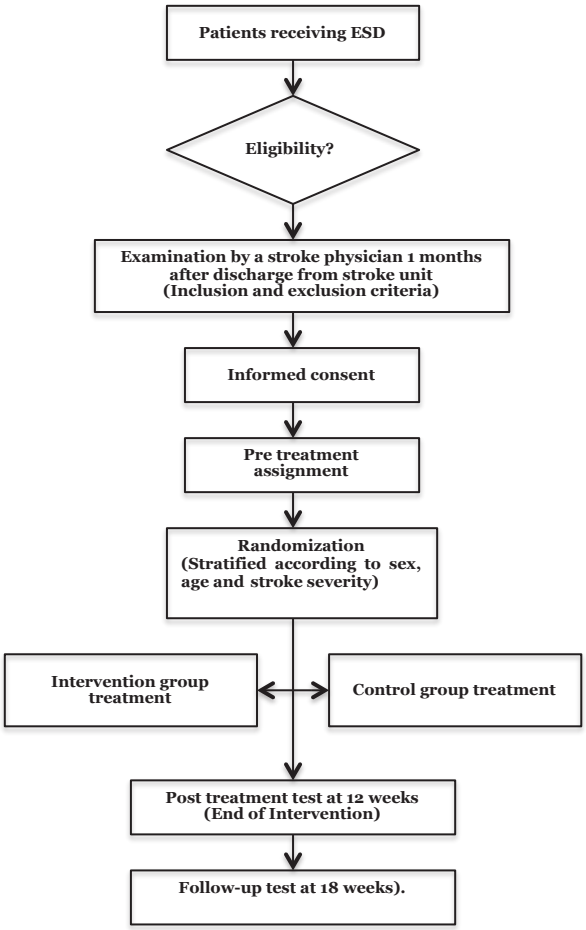

Figure 4. Flow chart for paper V.

Randomization process and power calculation

After an incremental cardiopulmonary exercise test (CPET) (117) on an ergometer cycle (pre-treatment test), the participants will be randomly assigned to the intervention group (n=25) or control group (n = 25). The randomization procedure will be web-based using program Minim (118) Minimization will be used to create and stratify groups (intervention and control) to ensure balance at study entry with respect to significant variables. The participants will be stratified according to sex, age, and stroke severity (modified Rankin Scale 0-1 vs ≥2). To decide on sample size, a power analysis was performed prior to the study. The power calculation was based on the level of fatigue assessed with the S-FAS. The absolute reliability of the

S-FAS is 9 points. Thus, a change of at least 9 points indicates a real change in the level of fatigue. With a power of 80% and significance level of 0.05 (2-sided t-test, assuming a standard deviation of 10), 21 persons per group are needed.

Cardiorespiratory training program

The intervention consists of a structured CITP on an ergometer cycle. The training will be carried out for 30-40 minutes, 3 days a week for 12 weeks. The individuals' training heart rate range, 70 to 80% of maximal heart rate (HR peak) will be set according to the pre-treatment test and CPET, and the Karvonen method (119). Each training session will begin with a 10 minutes warm-up (50% HR peak), followed by 25 minutes of 4x4 minute intervals, (70 to 80% HR peak) interrupted by 3 minutes of active recovery (50% HR peak) and 5 minutes of cool down (50 % HR peak). The participants will report their perceived exertion on the Borg Rating of Perceived Exertion Scale (120, 121) every minute during the 4-minute intervals. During the first weeks of training, an experienced physiotherapist will be present and guide the exercise sessions. As the exercise progresses and the participants become more familiar with the exercise, the physiotherapist will follow the training by phone or telemedicine equipment. During the CITP, the participants will wear a heart rate monitor and be instructed to exercise within the individual training heart rate range.

Outcome assessments

Feasibility will be measured by evaluating fidelity, adherence and adverse events. Fidelity will be measured by recording the number of sessions completed. Adherence will be measured by monitoring the patient´s heart rate during the exercise sessions. Adverse events will be recorded by asking the participants to fill in a home-exercise logbook at each training session and by reviewing hospital records. Post-stroke fatigue will be the primary outcome and cardiorespiratory fitness the secondary outcome.

The efficacy of the CITP will be assessed on the following outcome measurements:

- Post-stroke fatigue will be measured with the S-FAS (122).
- Cardiorespiratory fitness is determined by measuring peak oxygen consumption (VO_{2peak}) in an CPET on an ergometer cycle

The study was approved by the Regional Ethical Review Board in Umea, Sweden (Dnr 2015-420-31M).

Statistics (papers II-IV)

The Statistic Package for Social Sciences (IBM SPSS statistics) versions 18 and 21 were used for data analysis in papers II-IV. In study IV we also used Statistical Analysis System (SAS) for windows version 9. The baseline characteristics for the participants in papers II-IV were presented with frequency, proportion, mean, standard deviation (SD), and sometimes range and median.

In papers II, the two-sided Wilcoxon signed rank test (p-value <0.05) was used to compare differences (ADL-stair and RMI) within the same group at enrollment and discharge. The independent t-test (for continuous variables) and chi-square test (for categorical variables) were used in paper III to compare the groups at baseline. Multivariable logistic regression models were used to evaluate the association between PROMs and ESD. Each variable of PROM (satisfaction with rehabilitation after discharge, information about stroke, tiredness/fatigue, pain, dysthymia/depression, general health, and ADL dependency: mobility, toileting and dressing was analyzed separately. All models were adjusted for age, frequency of used thrombolysis, smoking, atrial fibrillation, country of birth, and education as independent variables. The results were presented as odds ratios (OR) with 95% confidence intervals (CIs). In the sensitivity analysis, the missing data (missing, unknown) were included in the reference category. Subgroup analyses were conducted to compare data from Umeå Stroke Center with other university hospitals and from Skellefteå hospital with community hospitals. The missing data were also included in the reference category in the subgroup analysis.

In paper IV, internal consistency was analyzed using Cronbach's alpha coefficient. An alpha value of 0.7 was acceptable and 0.90 excellent (123). The Fleiss-Cohen weighted kappa, k_w (124) was used to determine agreement between the test and retest for individual items. A $k_w < 0.20$ was considered poor, 0.21-0.40 fair, 0.40–0.60 moderate, 0.61–0.80 good and 0.81-1.00 very good (125).

To calculate absolute reliability (repeatability)(126, 127), a one-way ANOVA was used to estimate the within-subject standard deviation (S_w) from the square root of the within-subject residual mean square. The repeatability was estimated by $\sqrt{2} \times 1.96 \ S_w$ (i.e. 2.77 S_w), meaning that with 95% of differences between two measurements for the same subject, the measurement error is expected to be <2.77 S_w. We assumed that if the difference between two measurement occasions is >2.77 S_w the change in scores was due to a change in the condition.

The relative reliability was determined by a Bland-Altman plot (128) and the intraclass correlation coefficient ($ICC_{3,1}$) with 95% CI. An ICC score >0.70 was considered acceptable (129).

To measure if the S-FAS has sufficient span to capture differences, we investigated the presence of floor or ceiling effects. Floor or ceiling effects were presumed to be present if >15% of the participants achieved the lowest or highest possible scores (48, 130). Spearman's correlation coefficients were used to estimate the construct validity of the S-FAS. Correlations with $p < 0.05$ were considered significant. The correlation between the scales was considered strong (>0.5), moderate (0.35-0.5) or weak (<0.35)(131).

The analysis in paper V will be based on intension to treat. We will use two-sided students t-test or two-sided Wilcoxon signed rank test to compare intervention and control groups at pre-treatment test, post-treatment test, and follow-up test.

Results

Interviews with stroke patients about their experiences with hospital stay and discharge (Paper I)

The analyses of the interviews resulted in three main categories with subcategories (Table 4). The main categories were: responsible and implicated, depersonalized object for caring measures and "striving for repersonalization and autonomy.

Table 4. Categories and subcategories from analysis of interveiws

Subcategories	Categories
	Responsible and implicated
Confusion The health care staff knows and decide what I need Not knowing what you should ask about They have not got time Uncertainty about the function and organisation of care	Depersonalized object for caring measures
With mixed feelings Increased insights and understanding A wish for support from the health care service	The striving for repersonalization and autonomy

Responsible and implicated
All informants described being involved and to responsible in the decisions made at stroke onset.

"(…) I felt there was something wrong…so I got hold of it with my left hand instead and I thought that I had some sort of cramp (….) I felt sick. I thought it`ll pass off and I went inside (….) I feel my arm paralyzed and have no strength left in it (…) so we went directly to the health center" (Male)

Depersonalized object for caring measures
In contrast to involvement and decision-making at stroke onset, the informants took on a passive role during their hospital stay. They stated that the information about stroke and prognosis varied. Some received a lot of information while others missed information. During their hospital stay, it was not clear what information was missing. Their participation in planning of the discharge and follow-up was limited and the informants did not

question this decision. The informants relied on the hospital staffs' assessment and the organization and responsibilities were not clear. The informants' earlier experience and contacts with health care directed their expectations after discharge.

"Well, they said that, now, now…we have..eh, what shall I say… now we have decided that you can go home. That was all they said" (Male)

Some informants stated that the nursing staff had such a heavy work load that there was no time for information and they had unanswered questions.

"No, nothing about the clinical picture and the illness itself and why I have these symptoms and why it`s like this. Because they haven´t time for that sort of thing, it just fell in (new patients)." (Female)

Striving for repersonalization and autonomy
The longing to return home was described as an important factor for the recovery, but entailed mixed feelings. The informants felt both happiness and relief at returning home and anxiety and uncertainty about the new situation.

"If only I manage to get home I´ll get better". (Female)

After returning home the informants described a gradual adaptation to the new situation. The patients felt that they gained important insights and understanding about their stroke and its consequences. Against the background of their experience, the informants requested support from the health care service. The patients requested support, encouragement, reassurance, advice, and information about setbacks, prognosis, and medications. They also wanted confirmation that their recovery was progressing and that the exercises were suitable.

" So I could have told them… I can do this now and so on and they could said that I was managing fine" (Female)

The content, implementation, and effects of Umeå Stroke Center's ESD (Papers II- III)

Papers II-III describes and evaluates the development, content, implementation and effects of Umeå Stroke Center´s ESD as noted in the methods section of this thesis.

Implementation (paper II)

The development and implementation of the Umeå Stroke Center´s ESD started in September 2004. The ESD team was locally recruited and two team members with long experience in stroke care became responsible for the implementation process. The implementation process included working methods and procedures, the structure of team meetings, information to patients and families, and information meetings with officials in the municipality. Table 5 shows patients/year and the average and median length of stay in the ESD service for 2005-2015.

Table 5. Patient/year and length of stay in the ESD service

Year	Numbers of patients	Average length of stay	Median length of stay
2005	55	53	43
2006	67	35	30
2007	91	33	25
2008	78	21	15
2009	96	26	20
2010	140	23	17
2011	183	24	14
2012	205	22	13
2013	229	21	14
2014	225	20	12
2015	238	22	13

Initially the focus for the ESD team was to gain experience with the ESD method to increase confidence among physicians and the stroke unit team members. The ESD team accumulated experience by testing, performing the initial implementation, re-testing, and then performing further implementation. The ESD method was tested in patients with different stroke severity, different ESD resources, and at different times after stroke onset (directly after discharge from stroke unit or after discharge from in-

hospital rehabilitation units). It was concluded that it was important to adapt ESD to individual needs and that it may be possible to discharge stroke patients with more severe symptoms to the ESD service after a prolonged stay at the stroke unit. The analysis of the implementation according to CFIR is in Table 6.

Table 6. The analysis of implementation according to CFIR

Domain	Analysis
Intervention	Significant evidence for ESD, Systematic rewievs and National guidelines
Inner setting,	Stroke care organized in tree units
	Culture; share set of value "Do the best for the patients"
	Different perceptions between personal:
	Physicians responsible for shorten hospital stay and free up hospital beds
	Rehabilitation professional responsible to ensure the patient's rehabilitation.
	Positive implementation climate: ESD meets the need at the stroke unit
Outer setting,	Commission from the board -"top down approach"
Characteristics of individuals	Locally recruited from the stroke unit
	Two members had coordinator function:
	Long experience of stroke care
	Functioned both as formally appointed internal implementation leaders
	and champions.
	Large network
Implementation process	Started with a seminar about improvement in health care
	The ESD team consisted of interested individuals from different professions
	Started with few patients - test, retest, implementation (Plan-Do-Study-Act)
	Continuous evaluation with the value compass

Patient outcome (paper II)

Clinical status

A total of 153 patients fulfilled the inclusion-criteria for a final diagnosis of stroke and were included in the analysis. Thirty-two patients were excluded due to incorrect diagnosis (TIA n=24, other diagnosis n=8). The patients´ baseline characteristics are presented in Table 7. The patients had a mean

length of stay at the stroke unit of 8 days (range 2-57, median 7 days) and a mean length of stay with the ESD service of 23 days (range 1-132, median 17 days). One patient was re-admitted to the stroke unit due to concealed drug abuse

Table 7. Baseline characteristics, paper II

Variable	ESD patients n= 153	
Mean age (SD)	74	13,75
Women, n (%)	84	45
Median number of days at the stroke unit (Q)	7	5.0-11.0
Ischemic stroke, N (%)	142	93
Intracerebral hemorrhages, n (%)	11	7,2
Thrombolysis, n (%)	16	10,5
Living alone, n (%)	64	42
Dependent in activities of daily living, n (%)	8	5,2
Medical history, n (%)		
Previous stroke	36	23,5
TIA	11	7,2
Atrial fibrillation	34	22,2
Diabetes	24	15,7
Treatment for high blood pressure	88	57,5
Current smoker	14	9,2
Median functional status (Q)		
Modified NIH scale	1.0	1.0 - 3.0

NIH: National Institutes of Health; TIA: transient ischemic attack

Functional health status

The median score for ADL-stairs at enrollment was 3 ($Q_1 – Q_3$, 1 - 5) and at discharge 1 ($Q_1 – Q_3$, 0 – 3) ($p < 0.001$, two-sided Wilcoxon signed ranks test). The median RMI at enrollment was 11 ($Q_1 – Q_3$, 9 – 13) and at discharge 13 ($Q_1 – Q_3$, 12 – 15) ($p < 0.001$, two-sided Wilcoxon signed ranks test). The proportion of patients who were independent in ADLs (ADL-stairs 0-2) and mobility (RMI step 13-15) increased at discharge from the ESD compared to enrollment (Figure 5 and 6).

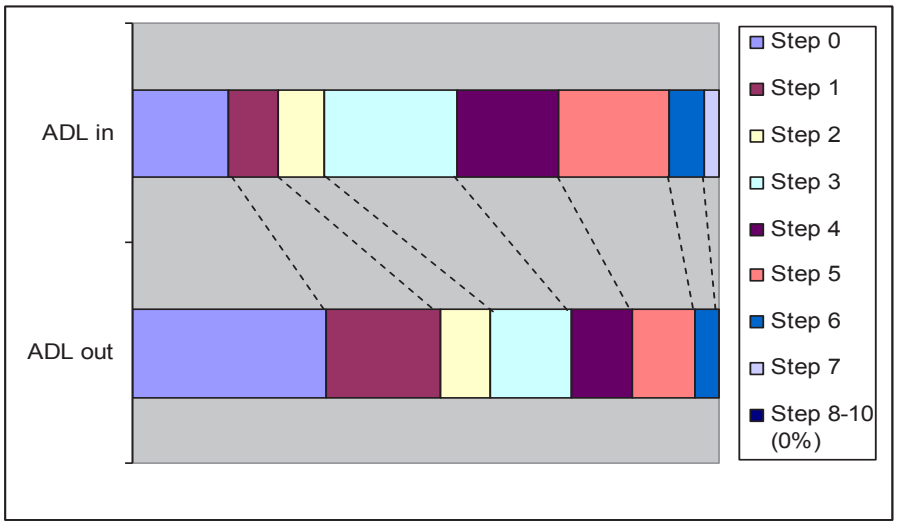

Figure 5. The percentage of subjects found at each step of the ADL-stair. Step 10 means that the individual is dependent on another person for all activities: at step 0, the person is completely independent.

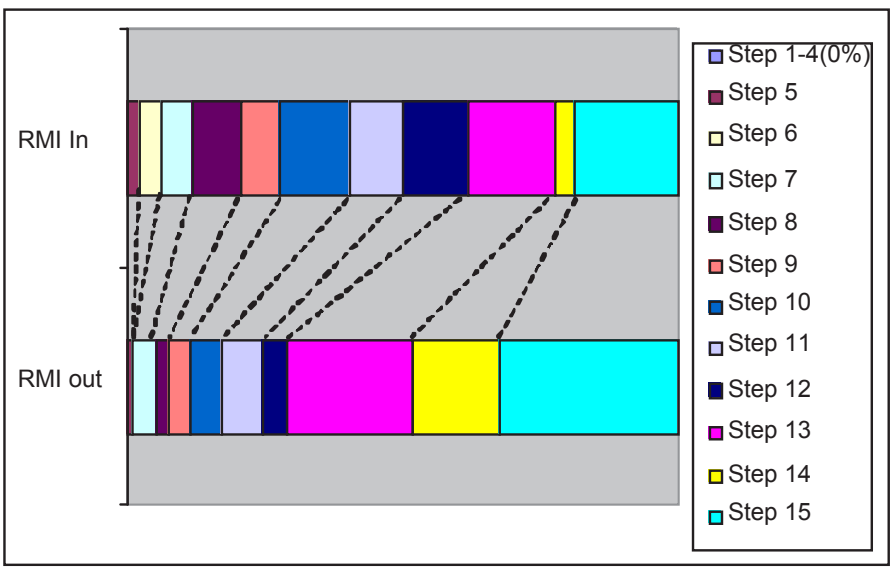

Figure 6. The percentage of subjects at each step of the RMI where a RMI score = 0 means poor mobility and 15 good mobility. RMI of 13-15 means completely independent out in the community.

Satisfaction in relation to needs

The Swedish National Patient Survey of Patient Satisfaction had a response rate among the ESD patients of 71 % during the study period. The patients were satisfied with the response, information, participation in care and treatment, and availability in care and treatment (Figure 7).

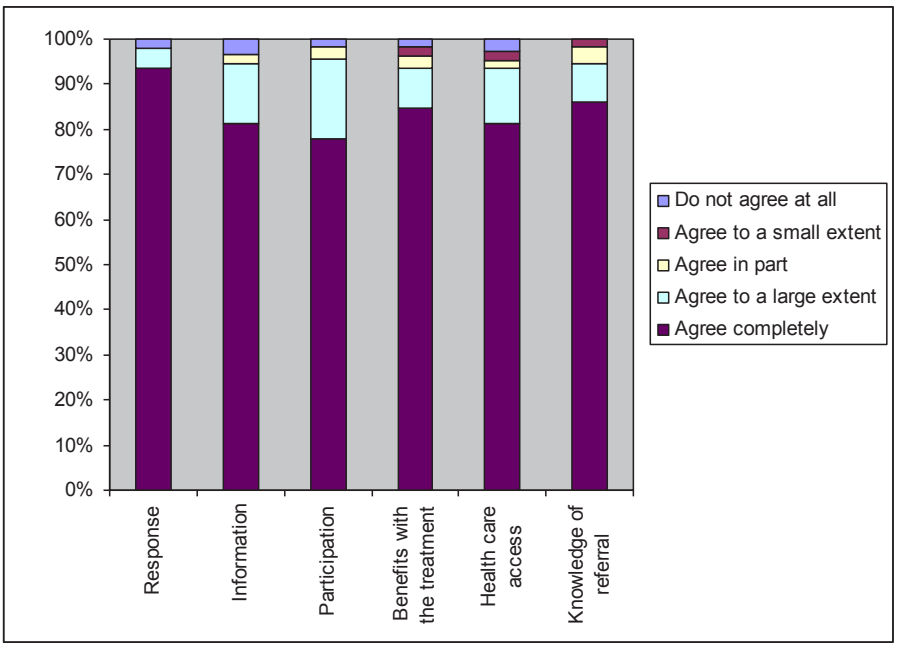

Figure 7. Patients' satisfaction in relation to needs according to the National Patient Survey.

Costs and resources

The mean number of home visits performed by the ESD team was 11 (median 8 visits per patient) and the mean time for each patient was 18 h (median 14 h per patient). The total number of home visits and total time spent by members of each profession are reported in Table 8. Approximately 71% of the patients received home visits from more than two team members and approximately 4% from the whole team.

The cost of one visit from the ESD team was estimated at 1143 Swedish Krona (132 €) (2013). During the same time period, the cost of care in the in-hospital stroke unit was estimated at 6259 Swedish Krona (722 €) per day. The estimated cost for the ESD service per patient was approximately 12 573 Swedish Krona (1429 €)

Table 8. Numbers of home visits and number of hours, by profession

Profession	Patients (n = 153)	Numbers of home visitits	total hours
		Mean (Range)	Mean (Range)
Nurse	110	1.3 (0-6)	2.4 (0.5-55)
Occupational therapist	148	4.5 (0-36)	7.5 (0.5-55)
Physical Therapist	148	4.5 (0-45)	7.1 (0.5-55)
Physician	7	0.1 (0-4)	0.8 (0.5-5)
Social worker	40	0.4 (0-5)	1.3 (0.5-13)

Accidental falls and injuries

From 1 January 2008 to 17 May 2009, 25 accidents were recorded in the Umeå University Hospital injury registry among individuals who received ESD. Nineteen persons (12%) were found in the registry: five recorded accidents on two occasions. The most common injuries were mild to moderate injuries (according to the MAIS), such as fractures and wounds. One person suffered a severe injury, a subdural hemorrhage (MAIS 4) after a fall.

Patient reported outcome (paper III)

During the study period, 99 833 patients were registered in the Riksstroke: 30 232 of these were included in paper III (Figure 6). The ESD group consisted of 1495 patients from Umeå Stroke Center (university hospital) and Skellefteå hospital (community hospital). The control group included 28 737 patients from 3 university hospitals, 13 other large hospitals, and 39 community hospitals. At baseline, the patients in the ESD group were slightly younger, had a higher education level, and were more often born in Sweden. There were also fewer smokers, fewer persons with atrial fibrillation and more frequent thrombolysis in the ESD group (Table 9).

Three months after stroke 1432 (96%) patients in the ESD group and 27 554 (96%) patients in the control group were still alive (total 28 986 patients). The multivariable logistic regression models of PROMs showed that the ESD group was more satisfied with rehabilitation after discharge (OR 1.36, 95% CI 1.10-1.67), were more independent in mobility (OR 1.45, 95% CI 1.17-1.80), toileting (OR 1.30, 95% CI 1.05-1.61), and dressing (OR 1.23, 95% CI 1.02-1.48) and had less dysthymia/depression (OR 0.68, 95% CI 0.55-0.84) than the control group. The analysis found no significant differences between groups for the variables information about stroke, tiredness/fatigue,

pain or general health. Tiredness/fatigue was more common than pain and depression (Table 10).

Table 9. Baseline characteristics of study participants (n = 30232)

Variable	**ESD group (n = 1495)**	**Control group (n = 28737)**	***p* value**
Sex, n (%)			0.212
Males	829 (55.5)	15461 (53.8)	
Females	666 (44.5)	13276 (46.2)	
Age, mean (SD)	73 (12.8)	74 (12.4)	0.001
Stroke subtype, n (%)			0.244
Ischemic Stroke	1314 (87.9)	25646 (89.2)	
Intracerebral hemorrhage	159 (10.6)	2741 (9.5)	
Undertermined	22 (1.5)	350 (1.2)	
Thrombolysis, n (%)	212 (14.2)	2252 (7.8)	0.001
Missing	1 (0.1)	142(0.5)	
Living alone, n (%)	605 (40.5)	12428 (43.2)	0.091
Missing data	4 (0.3)	97 (0.3)	
Mobility, n (%)			0.249
Independent indoors- and outdoors	1468 (98.2)	28088 (97.7)	
Independent indoors	27 (1.8)	649 (2.3)	
Hypertension, n (%)	817 (54.6)	16430 (57.2)	0.076
Missing data	3 (0.2)	107 (0.4)	
Diabetes, n (%)	250 (17.4)	5254 (18.3)	0.106
Missing data	0 (0.0)	40 (0.1)	
Atrial fibrillation, n (%)	282 (18.9)	6847 (23.8)	0.001
Missing data	0 (0.0)	102(0.4)	
Smoking, n (%)	157 (10.5)	4331(15.1)	0.000
Missing data	36(2.4)	2001 (7.0)	
Level of consciousness on admission, n (%)			0.123
RLS 1	1391 (93.0)	26419 (91.9)	
RLS 2-3	104 (7.0)	2318 (8.1)	
Length of hospital stay (SU), median (Q1-Q2)	5 (3-10)	6 (3-13)	0.92
Missing data	50 (3.3)	1220 (4.2)	
Education, n (%)			0.001
Primary School	527(35.3)	11902 (41.4)	
Secondary School	590 (39.5)	9930 (34.6)	
University	259 (17.3)	4428(15.4)	
Missing data	119 (7.9)	2470 (8.6)	
Country of birth, n (%)			0.001
Sweden	1431 (95.7)	25392 (88.4)	
Nordic countries *	41 (2.7)	1436 (5.0)	
Europe#	11 (0.8)	1234 (4.3)	
Other countries	9 (0.6)	466 (1.6)	
Missing data	3 (0.2)	209 (0.7)	

SU - Stroke unit

* Except Sweden

Except Nordic Countries

Table 10. Multiple logistic regression of patient reported outcome variables 3 months after stroke
(n = 28986) Odds ratio (OR) with 95 % confidence interval

Variable	ESD group (n = 1432)	Control group (n = 27554)	*p* value	oR	95% CI Lower	Upper
Satisfaction with rehabilitation*, n (%)						
Satisfied	507 (35.4)	9182 (33.3)	0.004	1.36	1.10	1.67
Dissatisfied	47(3.3)	1405 (5.1)		ref		
No need	449 (31.4)	9231 (33.5)				
Not received	44 (3.1)	1501 (5.4)				
Missing and do not know	385 (26.9)	6235 (22.6)				
Information provided about stroke, n (%)						
Satisfied	927 (64.7)	16820 (61.0)	0.051	1.20	1.00	1.44
Dissatisfied	82 (5.7)	1700 (6.2)		ref		
No need	87 (6.1)	3256 (11.8)				
Missing and do not know	336 (23.5)	5778 (21.0)				
Tiredness/fatigue, n (%)						
Seldom	780 (54.5)	15440 (56.0)		ref		
Often	410 (28.6)	8595 (31.2)	0.75	0.98	0.86	1.11
Missing and do not know	242 (16.9)	3519 (12.8)				
Pain, n (%)						
Seldom	956 (66.8)	19117 (69.4)		ref		
Often	217 (15.2)	4745 (17.2)	0.52	0.951	0.814	1.11
Missing and do not know	259 (18.1)	3692 (13.4)				
Depression, n (%)						
Seldom	1083 (75.6)	20819 (75.6)		ref		
Often	109 (7.6)	3118 (13.3)	0.000	0.68	0.55	0.84
Missing	240 (16.8)	3617 (13.1)				
General health, n (%)						
Good	988 (69.0)	19163 (69.5)		ref		
Poor	200 (14.0)	4779 (17.3)	0.09	0.87	0.74	1.02
Missing and do not know	244 (17.0)	3612 (13.1)				
Adl-independence, n (%)						
Mobility						
Independent	1146 (80.0)	21722 (78.8)	0.001	1.50	1.17	1.92
Dependent	83 (5.8)	2564 (9.3)		ref		
Missing	203 (14.2)	3268 (11.9)				
Toileting						
Independent	1117 (78.0)	21236 (77.1)	0.016	1.30	1.05	1.61
Dependent	112 (7.8)	3247 (11.8)		ref		
Missing	203 (14.2)	3247 (11.8)				
Dressing						
Independent	1075 (75.1)	20394(74.0)	0.03	1.23	1.02	1.48
Dependent	155 (10.8)	3895 (14.1)		ref		
Missing	202 (14.1)	3265 (11.8)				

* After Discharge

The proportion of missing response was 14,1-26.9 % in the ESD group and 11.8-22.6% in the control group. There was a higher proportion of missing responses in the ESD group for all variables. A sensitivity analysis was performed, categorizing missing/unknown/no need into the reference category. The ESD group still remained more satisfied with rehabilitation after discharge (OR 1.26, 95% CI 1.10-1.43) and less depressed (OR 0.68, 95% CI 0.55-0.84). There were no significant differences between the other variables (Table 10). Subgroup analyses for the university hospitals showed that the ESD group 1 (Umeå Stroke Center) was more satisfied with the stroke information provided (OR 1.23, 95% CI 1.05-1.44) and less depressed (OR 0.62, 95% CI 0.63-0.98). The subgroup analysis for community hospitals showed that the ESD group 2 (Skellefteå hospital) was less depressed (OR 0.69, 95% CI 0.49-0.97) (Table 11).

Table 11. Patient-reported outcome variables, 3 months after stroke (n = 28986) (sensitivity analysis)

Variable	ESD group (n = 1432)	Control group (n = 27554)	*p* value	OR	95% CI	
					Lower	Upper
Satisfaction with rehabilitation*, n (%)						
Satisfied	507 (35.4)	9182 (33.0)	<0.001	1.26	1.10	1.43
Dissatisfied #	925 (64.6)	18372 (67.0)		ref		
Information about stroke, n (%)						
Satisfied	927 (64.7)	16820 (61.0)	0.44	1.05	0.93	1.17
Dissatisfied #	505 (35.3)	10734 (39.0)		ref		
Tiredness/fatigue, n (%)						
Seldom	780 (54.5)	15440 (56.0)		ref		
Often and missing	652 (45.5)	12114 (44.0)	0.75	0.98	0.664	1.11
Pain, n (%)						
Seldom	956 (66.8)	19117 (69.4)		ref		
Often and missing	476 (33.2)	8437 (30.6)	0.523	0.95	0.81	1.11
Depression, n (%)						
Seldom	1083 (75.6)	20819 (75.6)		ref		
Often and missing	349 (24.4)	6735 (24.4)	0.00	0.68	0.55	0.84
General health, n (%)						
Good	988 (69.0)	19163 (69.5)		ref		
Poor and missing	444 (31.0)	8391 (30.5)	0.09	0.87	0.74	1.02
Adl-independence, n (%)						
Mobility						
Independent	1109 (93.0)	21722 (78.8)	0.001	0.78	0.68	0.90
Dependent and missing	323 (22.5)	5832 (21.2)		ref		
Toileting						
Independent	1132 (78.9)	21236 (77.1)	<0.001	0.78	0.683	0.88
Dependent and missing	352 (24.5)	6318 (22.9)		ref		
Dressing						
Independent	1077 (75.2)	20394(74.0)	0.001	0.81	0.71	0.92
Dependent and missing	355 (24.8)	7169 (26.0)		ref		

* After Discharge

Dissatisfied includes dissatisfied, No need, In need, did not received rehabilitation, and missing

Table 12. Subgroups analysis of patient-reported outcome variables 3 months after stroke (n = 18 417)

Variable	University hospital ESD 1 (n=928)	Control 1 (n=4636)	*p value*	OR (95% CI)	Small hospitals ESD 2 (n=504)	Control 2 (n=12349)	*p value*	OR (95% CI)
Satisfaction with rehabilitation*, n (%)								
Satisfied	338 (36.4)	1658 (35.8)	0.79	0.98 (0.84-1.14)	169 (33.5)	4024 (32.6)	0.73	1.03 (0.85-1,25)
Dissatisfied #	590 (63.6)	2978 (64.2)		ref	335 (66.5)	8325 (67.4)		ref
Information provided about stroke, n (%)								
Satisfied	590 (63.6)	2626 (56.6)	0.01	1.23 (1.05-1.44)	337 (66.9)	7683 (62.2)	0.42	1.08 (0.89-1.32)
Dissatisfied #	338 (36.4)	2010 (43.4)		ref	167 (33.1)	4666 (37.8)		ref
Tiredness/fatigue, n (%)								
Seldom	470 (50.6)	2337 (50.4)		ref	310 (61.5)	7256 (58.8)		ref
Often and missing	458 (49.4)	2299 (49.6)	0.13	0.88 (0.74-1.04)	194 (38.5)	5093 (41.2)	0.77	0.97(0.79-1.19)
Pain, n (%)								
Seldom	586 (63.1)	3074 (66.3)		ref	370 (73.4)	8794 (71.2)		ref
Often and missing	342 (36.9)	1562 (33.7)	0.29	0.89(0.72-1.10)	134 (26.6)	3555 (28.8)	0.82	0.97(0.76-1.24)
Depression, n (%)								
Seldom	660 (71.1)	3323 (71.7)		ref	423 (83.9)	9586 (77.6)		ref
Often and missing	268 (28.9)	1313 (28.3)	0.001	0.62(0.47-0.82)	81 (16.1)	2763 (22.4)	0.032	0.69(0.49-0.97)
General health, n (%)								
Good	604 (65.1)	3012 (65.0)		ref	384 (76.2)	8847 (71.6)		ref
Poor and missing	324 (34.9)	1624 (35.0)	0.03	0.78(0.63-0.98)	120 (23.8)	3502 (28.4)	0.25	0.86(0.66-1.11)
Adl-independence, n (%)								
Mobility								
Independent	683 (73.6)	3503 (75.6)	0.01	0.79 (0.64-0.94)	426 (84.5)	9868 (79.9)	0.23	1.17 (0.91-1.51)
Dependent and missing	245 (26.4)	1133 (24.4)		ref	78 (15.5)	2481 (20,1)		ref
Toileting								
Independent	670 (72.2)	3451 (74.4)	0.007	0.79 (0.64-0.94)	410 (81.3)	9609 (77.8)	0.68	1.05 (0.83-1.33)
Dependent and missing	258 (27.8)	1185 (25.6)		ref	94 (18.7)	2740 (22.2)		ref
Dressing								
Independent	647 (69.7)	3319 (71.6)	0.01	0.81 (0.68-0.98)	391 (77.6)	9219 (74.7)	0.72	1.04 (0.33-1.30)
Dependent and missing	281 (30.3)	1317 (28.4)		ref	113 (22.4)	3130 (25.3)		ref

* After Discharge # Dissatisfied includes dissatisfied, No need, In need, did not receive, and missing

Translation and evaluation of the psychometric properties of the S-FAS (Paper IV)

Translation

The two initial Swedish versions of the FAS were very similar. Pilot testing of the preliminary version of the S-FAS by two stroke subjects and evaluation by the expert panel resulted in some clarification of the questions.

Evaluation of the psychometric properties of the S-FAS

Ninety patients met the inclusion criteria and were invited to participate in the study. 72 agreed to participate (Figure 6). Baseline characteristics are summarized in Table 13.

Table 13. Baseline characteristics paper IV (n =72)

Variable	
Sex; n (%)	
Males	49 (69)
Females	22 (31)
Age, years, mean (range)	68 (39-87)
Diagnosis of stroke; n (%)	
Ischemic stroke	66 (92)
Intracerebral hemorrhage	6 (8)
NIH Stroke Scale, mean, (range), SD	2 (0-13) 2.8
Functional status in terms of mobility; RMI, n (%)	
Walk independently	67 (93)
Rehabilitation; n (%)	
Early supported discharge	58(80.5)
Other rehabilitation	2(3 %)
No rehabilitation	12 (16.5)

NIH Stroke Scale (NIHSS), SD: Standard Deviation,
RMI: Rivermead mobility index

The median time between stroke onset and the first assessment with S-FAS was 132 days (interquartile range, 115-148 days) and the mean time between test and retest was 9.6 days (SD, 3.3 days). The mean S-FAS score for test 1 was 24.6 points (SD, 4.6 points, median 24, range 16-37 points) and the mean S-FAS score for test 2 (retest) was 25 points (SD, 5.2 points, median 25, range 11-37 points). The number of missing responses between test and retest was 9 (12.5%) and the proportion of internal missing values was 0.1%.

Internal consistency, test-retest reliability and absolute reliability

The Cronbach's alpha (0.82) showed that the internal consistency of the S-FAS was good. The weighted kappa value (agreement between the test and retest of individual items) showed that the S-FAS ranged from fair to good (0.22–0.74). Five items had a kappa value defined as good (>0.60), four

items were moderate (0.40-0.60), and one item (item 10) was fair (0.22) (Table 14). The relative reliability of the total scores was good (ICC $_{3.1}$ = 0.73). The Bland-Altman plot in Figure 7 shows the test-retest reliability of total scale scores for the S-FAS. The absolute reliability (repeatability) was 8.8 (residual mean square = 10.167, one-way ANOVA: $\sqrt{2} \times 1.96 \times \sqrt{10.167}$ = 8.8). This implies that a change of at least 9 points is needed to ensure a real change in the fatigue level.

Floor/ceiling effect

The S-FAS revealed no floor or ceiling effect. None of the participants had the highest or the lowest total score (50 or 10, respectively).

Construct validity

The S-FAS correlated with both with the SF-36 subscale for vitality (r_s = -0.73) and the GDS-15 (r_s = 0.62) (Figure 8). This result suggests that the S-FAS had convergent construct validity, but not divergent construct validity.

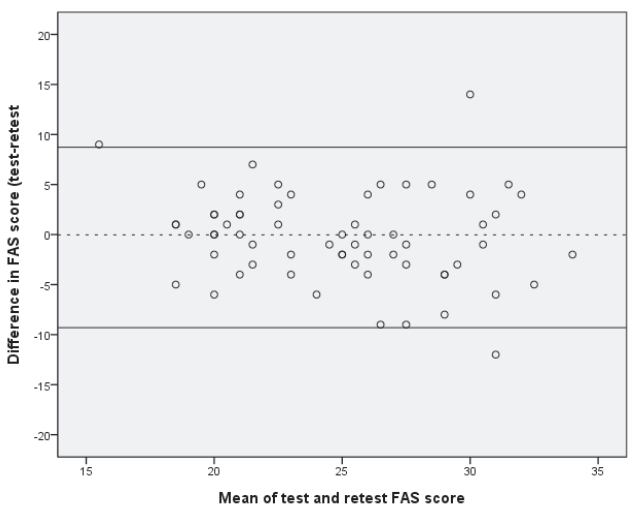

Figure 8. A Blandman-Altman plot of test-retest reliability of total scale scores for the S-FAS. Mean difference between test-retest (- - -) and the mean difference ± 2 SD (----).

Table 14. *Test-retest agreement for each item of the Swedish version of the FAS*

Item		Total number of ratings in each grade						Exact agreement	≤ 1 grade difference in agreement	Weighted Kappa value (95% CI)
		n	1	2	3	4	5	n (%)	%	Wk
1.	I am troubled by fatigue	63	23	61	15	23	4	43(68)	22	0.74 (0.61-0.87)
2.	I get tired very quickly	63	27	52	17	28	2	38(60)	33	0.74 (0.61-0.86)
3.	I only do a few things during the day	63	24	51	23	21	7	33(52)	32	0.57 (0.39-0.75)
4.	I have enough energy to manage my everyday life	63	4	25	13	32	52	38(60)	24	0.49 (0.24-0.73)
5.	I feel physically exhausted	63	39	55	11	18	3	35(55)	32	0.61 (0.45-0.78)
6.	I find it difficult to make a start on things	63	35	65	11	11	4	42(63)	32	0.40 (0.22-0.58)
7.	I experience problems with thinking things through	63	61	46	9	9	1	42(67)	24	0.64 (0.50-0.77)
8.	I feel no desire to do anything	62	20	53	41	6	6	43(70)	23	0.49 (0.25-0.73)
9.	I feel mentally exhausted	63	47	55	8	15	1	44(70)	22	0.64 (0.45- 0.84)
10.	I can concentrate quite well when I do something	63	6	21	10	43	46	31(49)	21	0.22 (-0.02-0.45)

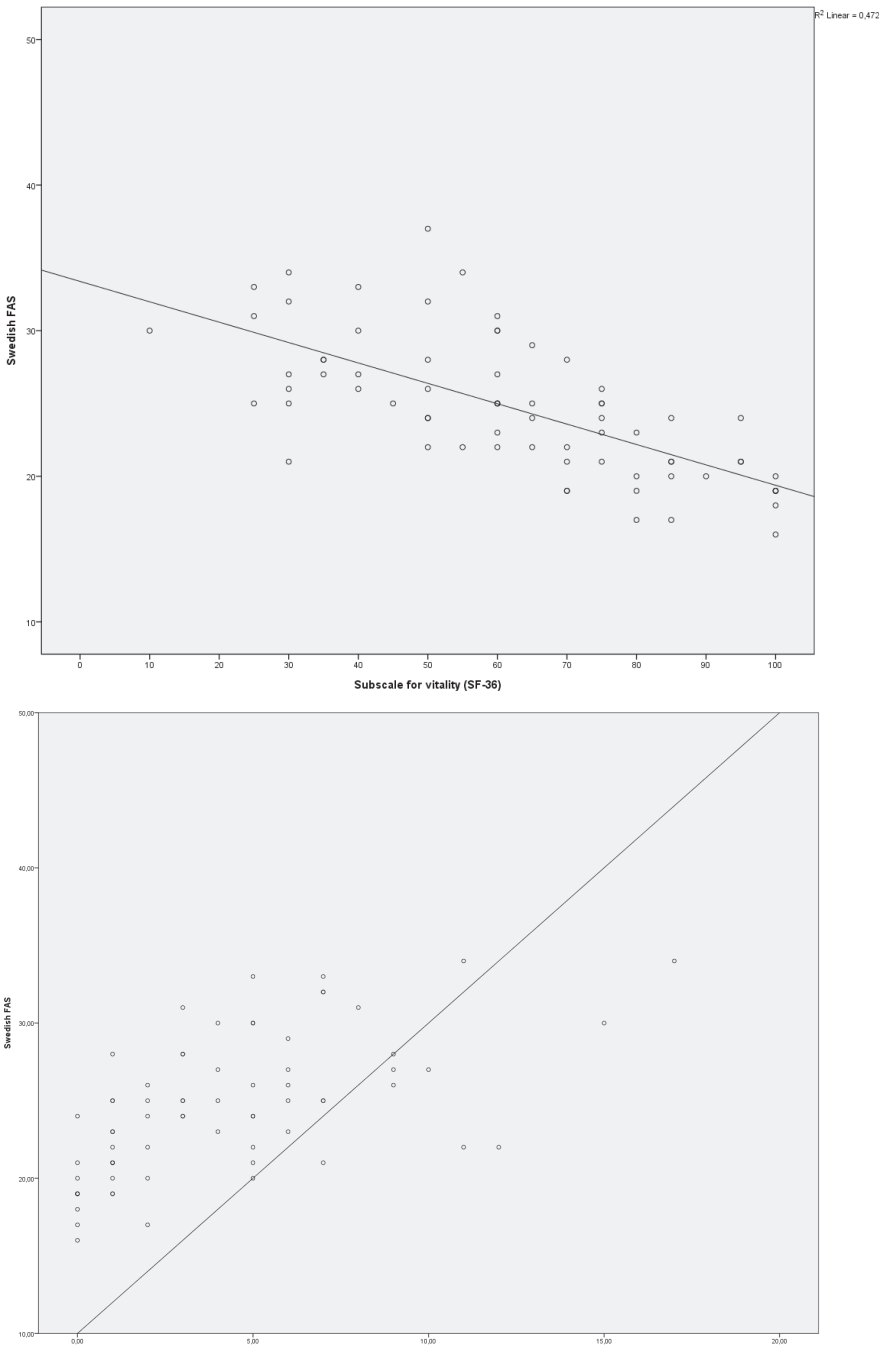

Figure 9. The correlation between the S-FAS and the SF-36 subscale for vitality (r_s = -0.73) and the correlation between the S-FAS and GDS-15 (r_s = 0.62).

Discussion

One main finding in this thesis is that it is possible to develop and implement an adapted ESD service for stroke patients based on the patients experience and request, evidence-based recommendations and local conditions. Another key finding is that patients receiving ESD according to the Umeå Stroke Center model reported that they were more satisfied with rehabilitation after discharge, had less ADL dependency, and felt less dysthymia/depression compared to patients who did not receive ESD after hospital discharge from the stroke unit.

This thesis also found that the S-FAS used at home as a self-administered questionnaire is reliable and valid for measuring fatigue in persons with mild to moderate stroke. The S-FAS can be a useful tool for measuring fatigue over time in different settings, and when evaluating different interventions targeting fatigue.

Interviews with stroke patients about their experiences with hospital stay and discharge

The findings in paper I indicate that returning home after discharge from the hospital involves the patient taking back responsibility and control over life again. Returning home gave the informants' important insights and understanding about the stroke and its consequences, and was an important factor in their recovery. The informants described mixed feelings about returning home - anxiety about the future but also happiness and satisfaction that things had gone alright. These mixed feelings were confirmed in a recent study (132).

After a while, the patients described a gradual adaptation to the new situation. The informants described how they found solutions to their new situation and saw results from the training. The patients progressed toward their own goals and felt confident that they were able to manage. They argued that it was important to their recovery to be hopeful. The salutogenic theory by Antonovsky (133) has been suggested to explain hope as an important coping resource in stroke rehabilitation (28). Antonovsky believes that the ability to cope with life experiences such as stroke depends on the individual's ability to master available resources. To mobilize recourses, the situation needs to be structured, manageable, or within the individual's control and seem meaningful.

The informants described that their participation in planning of the discharge and the follow-up was limited. They did not question this approach but relied on the health care staff and their competence. This passive acceptance can be explained from a perspective of the traditional medical model. In this model the patient's role is more passive and dependent, and the patient becomes an object for the caring measures. Here, it is important to note that the interviews were conducted 15 years ago. Today, this approach seems out of date because the established view of healthcare workers as experts is challenged (134). Nowadays, the patient is more closely involved in the planning of their own care and the aim of rehabilitation is to empower and support the patients' own process of recovery (135, 136). The informants requested information on their illness, recovery, prognosis, and medications. The majority wanted advice, support, and information about their state of health after discharge. This need for information and advice has been confirmed in other qualitative studies (24, 26, 27, 137).

According to an ICF perspective, the informants make us understand that the home environment (environmental factors) was a key component for recovery. The informants experienced increase in participation (activities/participation) in the home environment compared to the hospital. Hopefulness and the ability to copy with life (personal factors) were also important for the recovery after stroke.

In this paper, a qualitative approach was used to explore the informants' experiences with discharge. The use of in-depth, face-to-face interviews in a carefully selected study sample has been presented as a good way of gaining knowledge about experience. A qualitative approach can lead to a richer and more complete impression of stroke experiences, which can lead to greater understanding (138). A limitation of using a qualitative design is that it does not permit statistical generalization of the findings. Another way to find out the patients' experience of hospital stay and discharge could have been using a survey. With a survey it would have been possible to reach out to more patients, do statistical estimations and it may had led to a different result. Anyway, the insights from these interviews have provided important knowledge that has been useful in developing the locally adapted model for ESD in Umeå.

The content and implementation of the Umeå Stroke Center's ESD

It is difficult to transfer research from RCTs to clinical practice. When implementing a method (e.g., ESD service) into routine practice, it is often

necessary to adapt to local conditions (18, 83, 139). Studies on ESD have been criticized because they were not performed in modern stroke care with short hospital stay and access to hyper-acute therapies (29). The Umeå Stroke Center's ESD method was implemented in a setting with a mean of 8.6 days, i.e., a relatively short hospital total stay at the stroke unit and the use of hyper-acute interventions. This result is consistent with other studies of ESD in clinical practice (29, 30).

The working procedure and the amount of rehabilitation in the Umeå Stroke Center's ESD team can vary due to adaptation to each individual patients needs and goals. An example of this is that a maximum length of stay has not been established for the Umeå Stroke Center's ESD service. With this individual approach at the Umeå Stroke Center ESD, specific outcome variables were monitored and evaluated each year through the value compass (reported range of mean length of stay). The Umeå Stroke Center ESD responds to the requests by patients and their families about a more flexible and individually tailored ESD service (18, 23, 27).

To get a better understanding of what influenced the implementation of the ESD service, a retrospective analysis was carried out using the five determinants/domains presented in the CFIR. The successful implementation of ESD in Umeå was found to be due to a combination of factors. At first, the benefits of ESD was well-documented in RCTs and recommended in national and international guidelines (7, 12, 13). The method for ESD was adaptable to local conditions and considered cost-effective (18). The management had allocated funds and decided that an ESD team should be implemented in Umeå (top down approach). There was also a need for an ESD team linked to the stroke unit. The ESD team members were interested, engaged and had the opportunity to work independently with the local adoption and implementation of the method. Two ESD team members responsible for implementation functioned both as formally appointed internal implementation leaders and champions (139) that may have helped to facilitate the implementation. The ESD team worked closely with members of the stroke unit and gained experience about the ESD method. The locally adapted ESD service included routines for monitoring activities as the number of patients/year, length of hospital stay, re-admissions, satisfaction in relation to needs, and costs (92). These routines enabled evaluation of the ESD service. One result of the continuous monitoring is that the ESD service has expanded. Since May 2009, two ESD teams have operated with an increased catchment area (100 km).

The effects of Umeå Stroke center's ESD

The patients (papers II-III) who received ESD according to the Umeå Stroke Center model increased their independence in ADLs and mobility and were more satisfied with the service provided. This result is in accordance with previous research in clinical practice that demonstrated increased independence in ADLs and a higher level of satisfaction with the service received (29). Self-perceived tiredness/fatigue (Paper III) was more common than pain and depression. Approximately 30% of the patients reported self-perceived tiredness/fatigue. This result is in agreement with previous studies and confirmed that post-stroke fatigue is a common consequence after stroke that need attention (36, 38).

Prior studies of patient satisfaction regarding ESD have reported conflicting results (12, 13, 29). Patient satisfaction is difficult to investigate with care, as it can be influenced by the person's expectations, which depend on the patient's preferences, personality, and previous experience. Expectations of returning home with very early supported discharge and home rehabilitation have recently been described (132). The participants reported mixed expectations; the patients longed to return home but also described insecurity and fear. Despite these mixed expectations, the participants had high confidence that the ESD team would support them in being independent (132). Therefore, it is important that the ESD team participate in both the planning and coordination of discharge together with the patient and the family. This increase the chance that the patient and their family are informed and prepared before going home (13, 19).

Patients (paper III) who received ESD more frequently reported satisfaction with the stroke information provided and were less likely to feel dysthymia/depression compared to patients who did not receive ESD after discharge from the stroke unit. This result may be explained by the working procedure for the Umeå Stroke Center´s ESD team. In the Umeå Stroke Center model for ESD there is no specific key worker (case manager) appointed for the patient. Instead, it is considered to be a strength that the patient and their family to meet different team members. The team members provide consistent information and are able to work across professional borders. This approach is consistent with previous research suggesting that an active, rather than passive, information strategy is more effective in enhancing the patient´s and their family's knowledge. An active information strategy includes active participation with a subsequent plan for clarification and reinforcement (140).

Close cooperation between the patient, family members, and professionals in the patient´s home may also explain why the ESD group was less depressed. Depression is easier to detect and treat if it is possible to meet and evaluate the patient continuously. However, no difference was found between the ESD and control group in regards to self-perceived pain and fatigue. One explanation may be that there are medication and treatment guidelines for depression (141), but there is no consensus regarding treatment of pain and/or fatigue (142).

According to an ICF perspective, the participants who received ESD increased their independence and were more satisfied with rehabilitation after discharge (activity/participation). It is possible that the home environment (arena for ESD) can explain the increased satisfaction. The home environment (environmental factors) allows increased participation (activity/participation). The patient can be involved, set realistic goals for rehabilitation in close cooperation with family members and professionals (21-23). The participants who received ESD reported less feeling of dysthymia/depression, and self-perceived tiredness/fatigue was more common than pain and depression. Tiredness/fatigue, pain and depression are all examples of body function according to ICF. The ICF can also be used when describing baseline differences between the ESD and the control group (Paper III). The ESD group was slightly younger, had a higher education level, and was more often born in Sweden. Age, education, and ethnicity are personal factors according to ICF.

PROMs were used as outcome variables in paper III. A PROM is considered to measure how a person feels and includes symptoms, functional capacity, self-rated health, and health related quality of life, and can also include satisfaction with care and treatments (143, 144). Measurements of satisfaction and experiences with healthcare interventions (e.g., accessibility, information and response) are sometimes separated and called patient reported experience measurement (PREMs). According to this view, PROMs measure the patient's estimation of care in terms of health and symptoms and PREMs evaluate patient satisfaction or experiences with health care structures, processes and results (144). The Riksstroke follow-up includes both PROMs and PREMs. It is a strength to use an independent, large register with national coverage that is not associated with the caregiver. The Riksstroke PROMs for dysthymia/depression, fatigue, pain, general health, and ADLs (mobility, toileting, and dressing) have been validated against more established measurements increasing the reliability (4, 145). The validation report of Riksstroke PROMs (4) showed a good agreement with established measurements and accurate reliability. Good agreement between

the variables fatigue and ADL dependency was also shown in previous studies (145).

Translation and evaluation of the psychometric properties of the S-FAS

It is difficult to find a measurement that captures the complexity of post-stroke fatigue. We chose the FAS, because it is short, easy to administer, and recommended (48) and it has previously been tested in stroke patients (48, 50). According to the ICF framework, the S-FAS measures fatigue (body functions/structures) as well as how it affects every day life (activity/ participation). To ensure the quality of the translation process, we used a guideline (108) and considered cultural adaptation (146, 147). The results showed that the S-FAS is a valid and reliable questionnaire when it is self-administered by patients with mild to moderate stroke. This study also showed that the S-FAS has an absolute reliability of 9 points and no floor or ceiling effects. This finding is in accordance with previous studies (48, 50).

We used several statistical methods to ensure a robust investigation of construct validity and test-retest reliability, including absolute reliability and floor and ceiling effects. The study was designed so it would be possible to compare results for internal consistency (Cronbach's alpha), test-retest agreement for individual items (weighted kappa), and the relative reliability of the total score (ICC) with previous studies. The internal consistency of the S-FAS was good (Cronbach's $\alpha = 0.82$) and in agreement with a previous study (50). The test and retest agreement for individual items was varied, which was also reported in a previous study (48). The S-FAS showed good or moderate reliability for nine of 10 items. There were differences between the studies regarding the item with a lower kappa value. In our study, item 10, "I can concentrate quite well when I do something", had a substantially lower kappa value (0.22) whereas in the other study (48), items 1, "I am bothered by fatigue" and 8, "I feel no desire to do anything" had a lower kappa values. The varying results regarding the S-FAS may be explained by the items placement at the end of the questionnaire and the reversed scoring. Although the FAS is short, it is possible that the patients lost concentration at the end of the questionnaire or experienced different degrees of fatigue on the two test occasions. Post-stroke may include both physical and mental fatigue, and the latter comprises mental slowness and difficulties with concentration (148). Evidence suggests that attention, memory, and speed in information processing can be associated with fatigue (149).

The reason for choosing the FAS was that it should be easy to administer. We wanted to use a measurement that could also be used as a self-administered

questionnaire. The objective was for the FAS to be used in both the hospital and the patient´s home. It is satisfying that the relative reliability of the S-FAS (ICC 0.73) is largely in accordance with the finding of a study using the FAS in a face-to-face interview (ICC 0.77) (48). It might be assumed that there is a difference between providing answers in an interview and a self-administered questionnaire. The latter has the advantage of requiring less healthcare resources. The results indicate that the FAS is a questionnaire with distinct and easy-to-understand questions. The absolute reliability of the FAS had not been previously examined.

The absolute validity was considered important when the goal was to establish a measurement that can be used to both detect and evaluate interventions (150). The absolute reliability of the S-FAS was 9 points which may seem large on scale with a maximum score of 50. The investigation included participants with both low (11 points) and high (37 points) scores, and it seems reasonable that a 9 points change can occur if the fatigue level changes. However, it is important to gain experience with clinical application.

Because, there is no gold standard or widely accepted definition (38) of post-stroke fatigue, both convergent and divergent construct validity was investigated. In order to conduct the investigation, two established measurements were used: the SF-36 subscale for vitality and the GDS-15. We assumed that the S-FAS would measure fatigue like the SF-36 subscale for vitality and that the GDS-15 would measure depression. Our results confirmed convergent construct validity but not divergent construct validity. These results differ from an earlier study (50) that reported divergent construct validity when comparing the FAS to the Boston Depression Index (BDI) (151). An explanation of the varying results may be the use of different scales to evaluate depression. The GDS-15 identifies symptom of depression, whereas the BDI can identifies persons with depressive disorders and major depression (152). The correlation between fatigue and depression is not surprising, as they can be related in a complex way (40, 59, 149). This knowledge is of important when evaluating fatigue and other related conditions such as depression and pain (151).

The strengths of the current study are the consecutive inclusion, the data collection (self-administered), the analysis of absolute reliability and floor/ ceiling effects, and the targeted group of persons with mild to moderate stroke. This group of patients living in their own home represents a large proportion of the stroke population. Fatigue has been highlighted as a common disabling symptom in stroke survivors considered to be almost completely recovered (39). After discharge, the patients are not routinely

offered rehabilitative support for fatigue or psychological or cognitive impairment (40).

Methodological considerations

The papers in this thesis have limitations that need to be acknowledged. For example, the average length of stay at the stroke unit and time since discharge (25) are not described in paper I. This may complicate the readers' understanding of the setting that was explored. Unfortunately, patients with persistent aphasia did not participate in the study. Patients with aphasia at stroke onset were included, but none of the informants had communication difficulties when performing the interviews. Communication difficulties are common after stroke and in order to learn more from these patients it is important to include them in interview studies in order to learn more from these patients (25). The Miles and Hubermans model (93) was used to process and analyze the interviews. This is an overall model to process and analyze in different steps. The data reduction step can be questioned when there is a risk that relevant information can be lost. To discourage this, the data was reduced along a predetermined dimension that corresponds to the current issues (interview template) (90). Today, there are several more specific qualitative research methods that would have been preferable (138). The use of a more specific qualitative research method together with a electronically organization of data (qualitative data analysis software package) had probably increased the trustworthiness (154).

The implementation process (paper II) was analyzed retrospectively. This is a limitation, as it is important to plan and monitor the implementation process when introducing new methods into clinical practice. In this case, when initiating the ESD service in 2005, we did not have knowledge of implementation science. Implementation science is a relatively new research field with broader recognition of the need to establish a theoretical basis for implementation and strategies to facilitate implementation (85). With the current knowledge, the implementation should be planned and followed during the process to enable identification of hindering and facilitating factors (determinates), which could affect implementation outcomes. Today, there are several available frameworks that could have been appropriate to use to follow the implementation process (85). Evaluation of effects of the Umeå Stroke center's ESD method using the value compass did not include a control group, which means that it is not possible to distinguish the role of the ESD intervention from natural recovery in the effects on observed enhancement. There are also shortcomings in the reporting of accidental

falls or other injuries. The Umeå University Hospital injury registry only records cases reported at the emergency department at the hospital. This means that minor injuries not requiring care may not have been recorded. The reported satisfaction in relation to needs (paper II) should be considered with caution. The ESD team delivered the survey when the intervention was completed. The patients' positive attitudes can be an expression of continued dependence on the ESD team. There may also be an imbalance in missing cases, when non-responders may have been less satisfied. A problem regarding the use of PREMs or asking questions about satisfaction with care is that the patients may avoid complaining in order to not negatively affect their situation (144). The National Patient Survey only includes PREM questions about response, information, participation in care and treatment, and availability of care and treatment. Here, an independent survey had enable patients to answer more truthfully. It has been suggested that PREMs only should be used in independent surveys (144).

In paper III, the high proportion of missing responses, especially in the ESD group, is a limitation. The missing responses may lead to real potential benefits of ESD not being proven. The reliability of using PROMs in a stroke population can also be questioned and should be considered with caution. After a stroke, it is not unusual for the patient to initially have problems with memory, concentration, and fatigue, which can affect the reliability of the patient's response (149). An example of this memory problem is that approximately 30% of the participants in the ESD group reported that they had no need for rehabilitation after discharge. According to Riksstroke, these persons were scheduled for rehabilitation efforts with the ESD team. When interpreting the result that the patients in the ESD group were more satisfied with rehabilitation after discharge, it is also important to consider recall bias. The patients that respond may be those with a positive experience with rehabilitation after discharge.

In Paper IV, when evaluating the psychometric properties of the S-FAS the time of day when the questionnaire was completed and the time span between test and retest was not fixed. This is a limitation that may have affected the result. The degree of fatigue may be influenced by how active (physically and mentally) a person has been. It is therefore important that the person rate their fatigue in similar circumstances. A fixed time of day to rating fatigue but also an estimation of the level of activity (155) had added further to the results. Patients with severe stroke were excluded, which limits the generalizability of the results. It is possible that the persons who chose to participate in the study are those with experience with fatigue, so recall bias can also be considered. However, the results included persons reporting both high and low fatigue levels. The presentation of ordinal data as means can be

considered a statistical limitation. This choice was made to allow a comparison with the previous studies.

Clinical implications and future research

During the last decade, the length of hospital stay for stroke survivors has decreased. This can depend on many different factors, such as more effective care at the stroke unit, access to hyper-acute therapies, early rehabilitation start and more active prevention of risk factors. Despite national recommendations for stroke care, there has been no major expansion of ESD in Sweden (4, 7, 13). A gap exists between the recommendation of care and the care actually offered. This thesis shows that it was possible to adapt and implement an ESD service for stroke patients in modern stroke unit care with short hospital stay and access to hyper-acute therapies. The implementation of the Umeå Stroke Center ESD method (92) started more than 10 years ago. At that time, available research about the ESD method was used to guide the adaptation and implementation of a new method for stroke care and rehabilitation in Umeå. As mentioned before, it is difficult to describe in detail the working procedure, and there are useful consensus documents (18) available to guide the implementation of ESD.

Despite the previously shown benefits of ESD and home rehabilitation, further research is needed in today's stroke care. There is a need for research regarding ESD in stroke survivors with severe stroke symptoms and those living in rural areas. We also need to learn more about and incorporate expectations and experiences from the patients and their families to design a flexible an individual ESD service. It is important to evaluate the implementation process of ESD, which factors can facilitate or hinder the implementation. It is also important to further develop the ESD service and investigate whether it is feasible to use ESD and the home environment for targeted treatment of post-stroke fatigue. Today, there is a lack of evidence regarding the treatment of post-stroke fatigue. It should be advantageous to treat post-stroke fatigue in the patient's home when exhausting travels is to be avoided. This is the reason for planning a RCT to investigate whether a structured CITP added to the ESD service increases oxygen uptake and relieves post-stroke fatigue. The S-FAS was found to be a valid and reliable questionnaire useful evaluating post-stroke fatigue. Research of the S-FAS is needed to further investigate the divergent construct validity and how to distinguish between fatigue and depression. Research is also needed regarding the usability of the S-FAS to measure fatigue over time and in interventions targeting fatigue.

Conclusions

- Returning home gave stroke patients important insights and understanding about the stroke, its consequences, and was also an important factor in their recovery and rehabilitation.

- It is possible to develop and implement ESD services for stroke patients based on patients' experiences and requests, evidence-based recommendations, and local conditions.

- Patients who received modern stroke unit care and ESD according the Umeå Stroke Center model were more satisfied with rehabilitation after discharge, reported less ADL dependency and felt less dysthymia/depression than patients who did not receive ESD.

- ESD in the setting of modern stroke unit care with short hospital stays and access to hyper-acute therapies appears to have positive effects on rehabilitation in the subacute phase.

- The S-FAS used at home as a self-administered questionnaire is reliable and valid for measuring fatigue in persons with mild to moderate stroke.

- A study protocol has been formulated for a prospective randomized open-label trial with blinded evaluators, which will explore if CITP added to ESD compared with only ESD results in relieved post-stroke fatigue and increased oxygen uptake.

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Appendix

CVS-projekt 2000 Appendix I

Intervjumall

1. Kan du berätta vad som hände när du blev sjuk?

2. Kan du berätta om när du kom hem?

3. Kan du berätta om planeringen kring din utskrivning?

4. Fick du information vid utskrivning angående återbesök och uppföljning?

5. Har du träffat någon från din hälsocentral efter utskrivning från sjukhuset?
   - Vem/vilka/var?

6. Finns det något återbesök inplanerat?
   - Hos vem/vilka/var?

7. Vem är din läkare?

8. Kan du berätta om samarbetet mellan sjukhuset och din hälsocentral?

9. Upplevde du att den första kontakten med din hälsocentral efter utskrivning kom vid rätt tidpunkt?

10. Kan du berätta om dina kontakter med din hälsocentral?
    - Vad har varit bra/mindre bra
    - Vad har du saknat?

Svenska Fatigue Assessment Scale

Appendix II

Följande tio påståenden speglar hur du vanligtvis känner
För varje påstående kan du välja ett av fem svarsalternativ, från Aldrig till Alltid:
1= Aldrig, 2= Ibland, 3= Regelbundet, 4 = Ofta och 5 = Alltid
Sätt en ring runt det svarsalternativ som stämmer bäst för dig

		Aldrig	Ibland	Regelbundet	Ofta	Alltid
1	Jag är besvärad av trötthet	1	2	3	4	5
2	Jag blir väldigt fort trött	1	2	3	4	5
3	Jag gör få saker under dagen	1	2	3	4	5
4	Jag har tillräckligt med ork för vardagen	1	2	3	4	5
5	Jag känner mig fysiskt utmattad	1	2	3	4	5
6	Jag har svårt att påbörja saker	1	2	3	4	5
7	Jag har problem att tänka klart	1	2	3	4	5
8	Jag känner ingen lust att göra något	1	2	3	4	5
9	Jag känner mig mentalt utmattad	1	2	3	4	5
10	Jag kan koncentrera mig riktigt bra, när jag gör något	1	2	3	4	5