

# Stroke rehabilitation in the context of early supported discharge

Quantitative and qualitative aspects of daily life after mild-to-moderate stroke

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## Scientific environment

The research comprising this doctoral thesis was carried out in the Physiotherapy Research Group, Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway. It was anchored in the main research project entitled, Early Supported Discharge after stroke in Bergen, Norway (ESD Stroke Bergen) administered from the Department of Physical Medicine and Rehabilitation, Haukeland University Hospital, Bergen, Norway (ClinicalTrials.gov Identifier: NCT00771771). ESD Stroke Bergen is a randomized controlled trial organized as a collaboration between the University of Bergen, Haukeland University Hospital, and the Department of Health and Care in the Municipality of Bergen, Bergen, Norway. Important project co-operators at the Haukeland University Hospital are the Department of Occupational Therapy, the Department of Neurology, and the Department of Physical Medicine and Rehabilitation.

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As a PhD-candidate, I was granted admission to the Faculty of Medicine, University of Bergen. Doctoral training and PhD courses were provided by the Faculty of Medicine, the Department of Global Public Health and Primary Care, and through the Research Programme on Health Sciences at the Centre for Clinical Research, Haukeland University Hospital. My office was located at the Centre for Clinical Research during my PhD studies and research.



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## Abstract

Stroke affects mainly elderly people and is a major cause of disability worldwide. A primary focus in rehabilitation is stroke survivors' ability to engage in daily life.

Current evidence supports Early Supported Discharge (ESD) to home and follow-up rehabilitation in the municipality over conventional care in hospital. This view arises because promising results show that independent living in the community is possible, and patients who are mildly to moderately affected by stroke benefit the most.

However, we do not know which rehabilitation model in the municipality produces the best gain in stroke survivors' activities of daily living (ADL) ability, or how this new way of organising stroke rehabilitation is working for patients. The overall aim of this thesis work was to broaden our understanding of different aspects of daily life after stroke and ESD rehabilitation models in the municipality. We aimed to acquire more crucial knowledge about successful outpatient rehabilitation and to contribute to a more comprehensive understanding of what it means to live with mild-to-moderate stroke.

The objective of paper 1 was to compare three models of outpatient rehabilitation: ESD in a day unit, ESD at home, and traditional treatment in the municipality (control group). It was hypothesised that ESD models would result in superior outcomes in ADL ability (in terms of changed performance and independence) during the first 3 months after stroke. A group comparison study was designed within a larger, more comprehensive randomised controlled trial (RCT). Patients were tested with the Assessment of Motor and Process Skills (AMPS), a tool for evaluating the quality of ADL (performance and independence), at baseline and discharged directly to their homes. The AMPS was used as a primary outcome measure, and the modified Rankin Scale (mRS) was used as a secondary outcome measure. Included in the study were 154 stroke survivors (median age: 73 years), with an overall mild-to-moderate disability, a short stay in the stroke unit (median: 8 days), and no significant differences in baseline characteristics. Their baseline ADL scores indicated some

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functional limitations, and the AMPS revealed more problems than the mRS. We had a substantial lost to follow-up, with 103 patients being retested at 3 months. Compared to those who were retested, lost-to-follow-up subjects were older, lived more often alone, and had suffered a more complicated stroke. We found no significant differences when comparing pre-post changes in ADL scores between the rehabilitation groups. Within the group of patients who were retested, we found significant pre-post improvement for all the AMPS scores but no significant changes for the mRS scores. Controlling for possible confounding factors, patients in the ESD groups were, compared to the control group, significantly associated with improved ADL ability at 3 months measured by the mRS but not the AMPS. We concluded that further investigation is needed to find the best rehabilitation model to improve stroke survivors ADL ability. ESD rehabilitation may be beneficial to patients with participation restrictions or physical impairment after stroke.

In paper 2, the objective was to explore mild stroke survivors' experiences of living with stroke in the context of ESD and continued rehabilitation at home. The objective of paper 3 was to explore mild-to-moderate stroke survivors' experiences with home rehabilitation after ESD. Both studies were based on the same in-depth interviews anchored within a qualitative interpretative interview design, conducted in the context of the larger RCT. Eight patients between 45 and 80 years old from the home rehabilitation group were selected for the interviews. Extensive interview data formed the basis for paper 2 and paper 3. The empirical material for both papers were analysed using an interpretive approach and systematic text condensation. The coping theory, called Sense of Coherence, was used in later stages of the analysis to further deepen our understanding.

With this background in mind, in paper 2 our analysis focused on patient-attributed meanings of their changed body, their activity, and participation in the home recovery process after stroke. We found that living with mild stroke affected the participants' life on an existential level. Differences and similarities in experienced challenges were



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related to vital health issues, the body, and self-perception, which are dimensions that seem to complicate practical tasks and close relationships. Six to 8 months after the stroke, the participants were still living with unresolved rehabilitation needs. We concluded that mild stroke rehabilitation should focus more intensely on basic concerns related to vital health issues, the body, and self, which seem to complicate mild stroke survivors' entrance back into practical and social activities.

Comprehending their own changed body and sense of self seems to be a long-term process, even when living with mild stroke. We suggested that healthcare professionals should be more aware of stroke survivors who experience an uncertain situation and unresolved rehabilitation needs.

The focus of interest in paper 3 was on patient-attributed meanings of how ESD and home rehabilitation contributed to their recovery 6-8 months after returning home. We found that the process of recovery was motivated by a hope of attaining a life worth living. Crucial determinants to their hope were their ability to make sense of their now-altered body, as well as cultivating mutual confidence in the healthcare professionals with whom they were involved. Getting familiar with their changed body was an emotional process, an process for which the participants requested help. To accommodate stroke survivors' need of emotional support to foster the hope necessary to forge ahead, healthcare professionals' communication qualities and their ability to attend to individual needs were deemed important. We concluded that professionals involved in home rehabilitation should strive for cooperation among all stakeholders and build a flexible service based on individual needs. Increased attention to therapeutic communicative qualities, bodily changes, emotional processes, social relationships, and long-term follow-up might contribute to a richer and more beneficial experience for stroke survivors.

In summary, evidence provided by this thesis work on ESD models of rehabilitation after stroke does not clearly recommend ESD models over traditional rehabilitation in the municipality. This conclusion refers explicitly to outcomes of changed ADL

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performance and independence during the first 3 months after mild-to-moderate stroke. Existential and emotional challenges seem to be the core of what mild-to-moderate stroke survivors are struggling with even 6-8 months after onset.

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## Original papers

This thesis is based on the following three papers:

### Paper 1

Taule T, Strand LI, Assum J, Skouen JS. Ability in daily activities after early supported discharge models of stroke rehabilitation. *Scand J Occ Ther* 2015 [accepted for publication 14 April 2015]

### Paper 2

Taule T, Råheim M. Life changed existentially: a qualitative study of experiences at 6-8 months after mild stroke. *Disabil Rehabil.* 2014;36(25):2107-19. doi:10.3109/09638288.2014.904448. Epub 2014 Mar 26.

### Paper 3

Taule T, Strand LI, Skouen JS, Råheim M. Striving for a life worth living: stroke survivors' experiences of home rehabilitation. *Scand J Caring Sci.* 2015 Feb 4. doi: 10.1111/scs.12193. [Epub ahead of print]

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# Contents

SCIENTIFIC ENVIRONMENT.....	2
ACKNOWLEDGEMENTS.....	3
ABSTRACT.....	7
ORIGINAL PAPERS .....	11
CONTENTS.....	12
ABBREVIATIONS .....	15
CLARIFICATION OF CENTRAL TERMS AND DEFINITIONS.....	16
<b>1. INTRODUCTION .....</b>	<b>18</b>
1.1 STROKE .....	18
<i>Diagnosis</i> .....	19
<i>Epidemiology</i> .....	20
1.2 DAILY LIFE.....	21
<i>After stroke</i> .....	22
<i>Prognosis</i> .....	24
1.3 STROKE REHABILITATION.....	25
<i>Early intervention</i> .....	26
<i>Multidisciplinary approach</i> .....	27
<i>Individual therapeutic treatment</i> .....	28
1.4 PRECONCEPTIONS AND THEORETICAL MODELS.....	29
<i>International classification of function, disability, and health (ICF)</i> .....	29
<i>Health and disability</i> .....	29
<i>Salutogenesis</i> .....	31
<b>2. AIMS AND OBJECTIVES.....</b>	<b>33</b>

---

<b>3. MATERIALS AND METHODS .....</b>	<b>34</b>
STUDY DESIGNS .....	34
PATIENTS .....	34
<i>Inclusion and exclusion of participants in ESD Stroke Bergen and in studies 1-3</i> .....	36
DATA SOURCES .....	37
<i>AMPS</i> .....	37
<i>mRS</i> .....	39
<i>Qualitative research interview</i> .....	40
PROCEDURE .....	41
<i>Study 1 - Intervention study</i> .....	41
<i>Studies 2 and 3 - Interview studies</i> .....	44
DATA ANALYSIS .....	46
<i>Statistical data analysis</i> .....	46
<i>Qualitative analysis</i> .....	47
<b>4. SUMMARY OF RESULTS .....</b>	<b>55</b>
PAPER 1 .....	55
PAPER 2 .....	56
PAPER 3 .....	57
<b>5. DISCUSSION .....</b>	<b>59</b>
METHODOLOGICAL CONSIDERATIONS .....	59
<i>Study 1 - Intervention study</i> .....	59
<i>Studies 2 and 3 - Interview studies</i> .....	64
DISCUSSION OF FINDINGS .....	72

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<i>Main findings</i> .....	72
<i>Specific findings of study 1- Intervention study</i> .....	77
<i>Specific findings of studies 2 and 3 - Interview studies</i> .....	81
<b>6. CONCLUSIONS AND IMPLICATIONS</b> .....	<b>86</b>
<b>7. SUGGESTIONS FOR FURTHER RESEARCH</b> .....	<b>88</b>
<b>8. REFERENCES</b> .....	<b>89</b>
<b>PAPERS 1-3</b> .....	<b>101</b>
<b>APPENDIX</b>	
APPENDIX 1. MAIN TOPIC OF INTERVIEW GUIDE	
APPENDIX 2. SEARCH STRATEGY	

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## Abbreviations

ADL	Activities of Daily Living
AMPS	Assessment of Motor and Process Skills
ANOVA	Analysis of Variance
CT	Computed Tomography
ESD	Early Supported Discharge
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
ICF	International Classification of Functioning, Disability and Health
ID	Interpretive Description
MRI	Magnetic Resonance Imaging
mRS	modified Ranking Scale
NIHSS	National Institutes of Health Stroke Scale
PADL	Personal Activities of Daily Living
RCT	Randomised Controlled Trial
ROC	Receiver Operating Characteristic
SD	Standard Deviation
SOC	Sense of Coherence
STC	Systematic Text Condensation
TIA	Transient Ischemic Attack
WHO	World Health Organization

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## Clarification of central terms and definitions

The following key terms and definitions are central to this thesis:

### **Early Supported Discharge**

Early Supported Discharge (ESD) is defined as early discharge from hospital directly to the patient's home in the acute phase of stroke and is supported by follow-up treatment in the municipality when living at home [1]. ESD was originally designed to reduce the time of stay in hospital, and is promoted as an alternative to conventional in-hospital care [2].

### **The main research project - ESD Stroke Bergen**

A Randomised Controlled Trial that was established in order to compare the results of outpatient rehabilitation given in two different settings after ESD to results of traditional treatment in the municipality [3]. The two comparison settings were a day unit and the patient's home.

### **Daily life**

From the view of occupational therapy, a central concept is the ability to find meaning in the occupation of daily life [4]. Bringing meaning to one's daily life may involve aspects of 'doing', 'being', 'belonging', and 'becoming' [5].

### **Rehabilitation**

Rehabilitation (Latin: re=again and habitare=make fit) means restoring what is lost – compared to before a health threatening event– in order to meet future needs. In a national Norwegian document, rehabilitation is defined as: *'Time-limited, planned processes with clear goals and strategies, where several actors collaborate to provide necessary assistance to the patients' own effort to achieve the best possible functioning and coping ability, independence and participation socially and in society'* [6].



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**Stroke**

Stroke 'is' defined by the World Health Organization as: '*Rapidly developing clinical signs of focal (at times global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin*' [7]. The National Institutes of Health Stroke Scale (NIHSS) can be used to differentiate between mild stroke (NIHSS  $\leq 7$ ), moderate stroke (NIHSS 8-14), and severe stroke (NIHSS  $\geq 15$ ) [8].

**Stroke Unit**

A stroke unit can be described as an organisation responsible for stroke care in a hospital ward, where stroke survivors are provided a complex package of care by a multidisciplinary healthcare team, specialised in stroke management [9].

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# 1. Introduction

Stroke affects mainly elderly people [10] and is considered to be a major cause of disability worldwide [11, 12]. The after-effects of stroke are extensive, and rehabilitation targets stroke survivors' ability to participate in daily life [13]. Enabling people to engage as fully as possible in their daily life is also a major focus of occupational therapy [4] and forms the basis and motivation for conducting this thesis work. In order to regain independence after stroke, initial treatment in a hospital-based stroke unit, followed by Early Supported Discharge (ESD) from hospital and further follow-up rehabilitation initiated as early as possible when living at home is recommended [1, 9]. There is strong evidence to recommend this type of post-stroke treatment. ESD and follow-up rehabilitation in primary healthcare, however, is organised in different ways [14]. Moreover, when it comes to the ability to perform activities of daily living (ADL), one rehabilitation model cannot be recommended over others [1]. Calls for knowledge and understanding have been made for how the new organisation of rehabilitation is working out for patients [15-17]. To enhance ESD and follow-up rehabilitation in the municipality, qualitative and quantitative aspects of daily life need to be assessed.

## 1.1 Stroke

Stroke is caused by disruption of the blood supply to the brain. The World Health Organization's (WHO) definition of stroke includes events of ischaemic stroke and haemorrhagic stroke [7]. Transient ischaemic attack (TIA) is excluded from this definition.

Ischaemic stroke is characterised by a vascular blockage resulting from too little blood supply to part of the brain [18]. Haemorrhagic stroke is caused by rupture of a blood vessel and results in too much blood to parts of the brain [18]. In recent years, the definition of TIA has evolved. The classic definition focuses on temporary and

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transient neurological symptoms. However, results derived from newer technologies have led to a revision of this definition, recognising that TIA also has more permanent consequences [19]. In a Norwegian in-hospital population, 85% of all strokes are reported to be ischaemic in origin and 15% are haemorrhagic in origin [20].

The most important risk factors for stroke are advancing age, hypertension, and certain lifestyle factors, like tobacco use [21]. Diabetes mellitus is also an important risk factor [21].

## **Diagnosis**

Stroke is diagnosed on the basis of physicians' clinical assessment, standardised neurological examination, and neuroimaging procedures [13]. Clinical indication of stroke manifests as rapidly developing neurological symptoms or new symptoms on awakening, especially when lateralised to one hemisphere [22]. The most common sign is motor impairment with loss or limited control of movement, typically in the face or extremities [23]. This indication is present in about 80% of stroke patients [23]. Other indications of stroke may be cognitive decline like problems with memory or concentration, impaired communication abilities, mood disruption, or dysfunction in sensory, visual, or perceptual functions like neglect or apraxia [23].

Neurological examination is commonly carried out by using the National Institutes of Health Stroke Scale (NIHSS) [8]. High scores are associated with a high probability of stroke [22].

Neuroimaging involves brain scanning with computed tomography (CT), commonly employed soon after hospitalisation [24, 25], or scanning with magnetic resonance imaging (MRI). CT is used to rapidly exclude haemorrhagic causes that, if present, would preclude the use of thrombolytic treatment [26]. MRI is considered to be the most sensitive method to diagnose ischemic causes of stroke [26].

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Consistency in findings from clinical examination in the acute phase to neurological examination and neuroimaging contribute to the most confident and accurate diagnosis of stroke [22]. An accurate and timely diagnosis is crucial, most importantly for survival but also for mitigating possible long-term effects of stroke.

## **Epidemiology**

Worldwide, every year about 15 million people suffer a stroke [21]. From the 10 million who survive, 5 million are left with permanent disabilities [21]. Stroke was the third leading cause of disability worldwide in 2010 [27]. Marked geographic differences in incidence, survival, and prognosis in favour of high-income countries are reported [10, 12, 28].

In many high-income countries, the incidence of stroke is declining due to improved strategies for stroke prevention, such as smoking cessation and control of high blood pressure, high cholesterol, and prevention of blood clotting [21]. Over time, the trends of incidence seem more uncertain [20], partly because of a disconcerting and growing prevalence of diabetes and obesity in increasingly younger-aged patients [29]. Today one-half of first-time strokes occurs in the population aged 75 years and older, and the mean age of stroke incidence has increased during the last two decades [10].

Demographic changes in the population, in particular longer life expectancy and increasing proportions of people reaching very old ages, have resulted in more people each year experiencing stroke [10, 21]. Together with a markedly better prognosis – indicated by a 37% decline in age-adjusted stroke mortality during the last decades and probably a result of improved healthcare service – the prevalence of stroke survivors will likely increase in the future [10].

In Norway, stroke incidence is estimated to be 15,000 people every year, and the mean age of first-time stroke is 75 years for men and 78 years for women [20]. However, geographical differences occur in Norway also. In the area of Bergen between 2007 and 2009, for example, there was a low incidence rate (105 per 100,000 citizens per

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year) in patients with cerebral infarction admitted to a stroke unit [30]. From this population, 25% are estimated to need follow-up rehabilitation [31].

## 1.2 Daily life

As most patients survive the initial stay in hospital, the focus in rehabilitation will gradually shift from survival to helping patients figure out how to continue with life in a purposeful way. Living a meaningful daily life involves aspects of ‘doing’, including what people need to, want to, or are expected to do [4]. This mindset is the traditional preoccupation of rehabilitation, one focusing on purpose and outcome [5].

Investigating this aspect of ‘doing’ in daily life is an important area of quantitative research and implies a focus on patients’ ability to perform ADL, and what might contribute to independent ADL performance.

The term ADL describes routine, goal-directed tasks and actions that are necessary for accomplishing practical daily activities in everyday life [32]. Self-maintenance of basic physical or personal needs like toileting, dressing, and walking are called personal activities of daily living (PADL), while the term instrumental activities of daily living (IADL) or extended ADL is used to describe maintenance of home and domestic activities [33]. IADL may include preparing one’s own meals and transporting oneself but also may include activities related to personal preferences and interests [32]. Compared to PADL, IADL requires a higher level of physical, cognitive, and social competence, as well as the ability to use equipment and interact



Photo: Anne Sidsel Herdlevær

with the environment [34]. PADL and IADL constitute part of routine assessments in stroke rehabilitation [13]. Standardised outcome measures are preferred and recommended to implement in randomised controlled trials (RCTs) [35].



Illustration:  
Gorill Skaale Johansen

Creating a meaningful life may also involve existential aspects of daily life, like the experience of being and belonging [5]. The dimension of being can be understood as one that includes time to reflect on one's life, rediscovering oneself, as well as being present in the 'here and now'. This may mean taking part in and really embracing the 'small' and taken-for-granted situations, like enjoying being with someone special or appreciating nature. These aspects of being do not necessarily involve doing things by oneself. Belonging includes having fellowship with others, like having a sense of being included, and having mutual relationships. This includes a sense of affirmation that one's life has value to oneself as well as to others [5]. Valued activities may be related to employment, roles at home, leisure, or socialising [36].

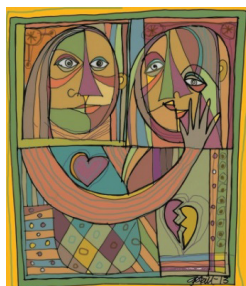


Illustration:  
Gorill Skaale Johansen

Another existential aspect of daily life is 'becoming', which is based on the idea that making life worthwhile after a major life disruption like stroke may involve re-thinking future dreams and hopes, exploring new opportunities and thereby achieving adjustment or transformation into a new reality [5].

The experiences of being, belonging, and becoming are central themes in qualitative studies of first-person perspectives [5].

The predominance of quantitative research in stroke research might indicate that healthcare professionals primarily emphasise acquiring objective knowledge related to the 'doing' aspect of daily life in their search for evidence-guided decisions.

## After stroke

In quantitative research, activity limitation and restrictions of participation of patients in daily life are commonly explained by underlying bodily impairments. This can refer to, first of all, motor impairments like hemiparesis, which affects almost half of all stroke survivors [23]. However, cognitive problems may also help explain the variance

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among stroke survivors in achieving independence [37], and is thought to affect about 30% of patients with first-time stroke [38]. Mood disruption is another, often ignored complaint with possible effects on ADL [39]. Furthermore, fatigue – described as a subjective feeling of having a lack of physical and mental energy [40] appears to be a severe problem for 36% to 77% of all stroke survivors [41]. Limited ADL skills may result in difficulties in living independently at home and maintaining one's previous lifestyle [42]. However, limited ADL skills and restricted participation might also be a risk factor for depression and lower quality of life [43-46].

A synthesis of qualitative research leaves little doubt that suffering a stroke is experienced as a sudden and overwhelming transformation of life, leading to emotional strain in those affected, and is followed by possible loss, uncertainty, and social isolation [47]. Loss may be related to functional ability, independence, and social life, while uncertainty is related to the future and who to 'become' after stroke [15]. Limited ADL skills contribute to loss of social contact and valued roles, particularly among older stroke survivors [48]. Inability to resume previous valued activities and problems dealing with bodily changes affect determination of self and identity [36, 49-51]. After stroke, feelings of uncertainty and frustration [52] may be reinforced when combined with well-known life disruptions like fatigue [40, 53, 54], mental slowness [55], and social isolation [56]. Uncertainty may also be related to fear of relapse [52], or other lifestyle disruptions, like making necessary changes in one's previous lifestyle, or taking new medications without knowing the side effects [57]. Being dependent on an unfamiliar healthcare system [54] may also contribute to a feeling of loss of control with the entire life situation [52].

Previous research indicates that tension may exist between the traditional focus on physical after-effects of stroke and how stroke survivors experience stroke as an emotional life disruption [52, 58].

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## Prognosis

Attaining independence in ADL has the lowest incidence immediately after stroke but increases thereafter [59]. Major improvement in performing ADL and participation in social life occur within the first 3 months [8, 60-62], but may continue to improve for up to 2 years after stroke [60]. At 3 months, poor PADL performance is reported for only 25% of the patients, while about 50% have poor IADL performance [63].

Attaining long-term independence after stroke is believed to be determined by achieving high ADL scores at discharge from hospital [64]. The finding that half of the patients in a Norwegian stroke unit population was independent in terms of ADL performance just one week after stroke onset [31] indicates that the prognosis of gaining independence can be good in many stroke survivors. However, other studies have reported less promising results. For instance, one study reports that 42% of patients, even 2 years after stroke, did not leave the house as much as they wanted, and 36% were unable to dress themselves without help [65]. This raises the possibility that some stroke survivors may be ill-prepared for community living.

As stroke occurs mostly in the elderly, it is worrisome to find an association between poor PADL scores at discharge and poor IADL scores for up to 3 years after stroke onset in older patients [66]. An association has also been reported between increased age and decline in ADL ability among stroke survivors [62, 67]. A number of studies have, however, reported other individual factors that predict ADL improvement and independence after stroke, such as different kind of prior stroke comorbidities, gender, initial brain site and size of stroke, socioeconomic status, severity of paresis and cognitive deficit, as well as how well patients accept their situation [61-64, 68-70]. However, comparing disability estimates from different studies is difficult because of inconsistency in study populations, outcome measures used, time of disability was assessed, and the fact that many stroke survivors are already disabled to some extent before stroke [71].



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From stroke survivors' point of view, regaining previously valued roles, abilities, and sense of self seem to be an ongoing struggle, even years after stroke [72]. This persistent situation poses a potential threat to stroke survivors' social existence [73]. Creating a balance between expectations of themselves and their own physical capacity seems crucial to success [74]. Regaining a meaningful daily life appears to be complicated by difficulties patients have with reconciling their post-stroke altered body with their previously perceived body [51, 75, 76], but also by negative thoughts and feelings of loneliness [76]. Dealing with a changed and unpredictable body involves not only hard physical work but also substantial psychosocial work by the patients [77]. Additionally, the presence of a number of personal factors, like patients' coping strategies and contextual factors that relate to social support and professional help, are critical to consider [36, 50, 78-80]. Negative impact on social life seems to particularly affect people aged over 70 years [48]. The finding that even mild-to-moderate stroke survivors experience themselves as more or less independent in their ADL and insufficiently recovered for a long time after stroke onset [36, 50, 52, 77, 81-83] indicates there is poor agreement between what is captured by standardised assessments and what is perceived by stroke survivors. This may suggest that use of quantitative assessment tools are less valuable in the absence of supplementary first-person information from the perspective of the patient [84, 85].

### 1.3 Stroke rehabilitation

In Norway, stroke rehabilitation is required by statute for all municipal healthcare services [86]. National documents explicitly state that stroke rehabilitation must target the patient's ability to take part in daily activities and participate in social life despite any disabilities caused by stroke [6]. To ensure high-quality care, there are clear recommendations to start intervention as early as possible after stroke onset and to apply both a multidisciplinary [35] and individualised approach [65].

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## **Early intervention**

### **Stroke unit**

In Norway, stroke units are part of the specialised healthcare service responsible for diagnosis and treatment [87]. There is reason to believe that about 90% of all stroke survivors in Norway are admitted to hospital [20], indicating that stroke-unit care is received by most stroke survivors. Patients who receive treatment in stroke units are more likely to regain independence soon after stroke and remain independent in the long run compared to patients who receive less organised conventional care [9].

### **Early supported discharge (ESD)**

ESD models of rehabilitation were introduced in order to shorten the duration of initial stays in hospital after stroke. The first ESD studies showed promising results, reporting a decrease of 8 bed days for patients who received ESD intervention [2]. In a Norwegian study from 2000, the average in-hospital stay was 19 days for patients who received extended stroke unit care with ESD [88]. Since the first studies on ESD, however, there has been a shift in healthcare policy in Norway, and indeed in other countries, to aim for shorter in-hospital stays for all patients [89].

Comparing ESD and follow-up rehabilitation at home with conventional care in hospital, patients receiving ESD are more likely to become independent, especially when suffering mild-to-moderated disabilities as a result of stroke [1]. A positive effect for patients' IADL scores soon after stroke failed to stand, however, in the long term. Moreover, no effect of ESD was reported for patients' PADL scores [1]. A systematic review that included patients who received physiotherapy concluded that early discharge and home rehabilitation probably would contribute to greater improvement in patients' IADL scores than for their PADL scores [14]. Another review comparing home rehabilitation with rehabilitation delivered in a centre (day

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hospital or outpatient clinic) reported benefits in functional independence in favour of home-based rehabilitation for up to 6 months after stroke [90].

ESD intervention, however, has turned out to be organised in different ways [14], and healthcare professionals are left with few clear recommendations for implementing follow-up rehabilitation in the municipality and how to support gains in stroke survivors' ADL abilities. Additionally, concerns have been raised about the psychometric qualities of some of the commonly used ADL outcome measures applied in RCTs, including their possibly limited sensitivity in detecting change [91] and the possible presence of ceiling effects [92]. If these concerns stand, it means that stroke survivors might reach the particular instrument's best score at baseline, masking any real improvement that might be detected by more sensitive instruments.

From a patient's perspective, life disruption and process of change become obvious once returning home [16]. At the same time, expectations of prognosis might be high and unrealistic upon homecoming [74, 93]. This indicates a vulnerable period for patients during which healthcare professionals should pay extra attention. Stroke survivors request also a smoother transition between ESD and ongoing rehabilitation services [94]. Explicit calls have been made to further explore how new ways of organising stroke rehabilitation is working out for patients [15-17]. More knowledge and understanding of stroke survivors' experiences of care pathways might help to ease the individual process of recovery.

## **Multidisciplinary approach**

Multidisciplinarity is a highly recommended framework for implementing stroke rehabilitation and ESD [35]. Important success factors to have are cooperation between healthcare professionals at different levels of healthcare and treatment provided by stroke-specific and multidisciplinary teams [1, 35, 65]. Additionally, it is highly recommended that an ESD intervention should be coordinated by a hospital-based ESD team, incorporating at least an occupational therapist, a physiotherapist,

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and a nurse, all specialists within stroke rehabilitation [35]. While some have stressed the importance of the team having academic and specific stroke-related qualifications [1, 35, 95, 96], others have pointed to the importance of focusing on healthcare professionals' personal qualities. These could be manifested as superior relational skills and presence in situations [17, 54]. Little is known, however, about the skills necessary to make a successful stroke therapist [65].

Stroke survivors themselves seem to appreciate skilled professionals who also understand their situation [97]. This may involve treating the patients with dignity and respect [98] and providing sufficient emotional support [54].

### **Individual therapeutic treatment**

Treatment guided by patients' needs and shared decisions between healthcare professionals and patients are valued goals in stroke rehabilitation [65, 99]. Interventions are beneficial when they comply with post-acute stroke guidelines, ones producing high ADL scores [100]. Complying with guidelines may involve repeated and intensive practise of functional skills and activities that have meaning to the patient (i.e., task-specific treatment) [65]. Reduced function and training are foci of healthcare professionals during the first year of rehabilitation [52].

From patients' point of view, successful rehabilitation may be related more to adjusting to a new situation and achieving a meaningful life, rather than regaining the ability to perform specific physical tasks [73, 101]. However, task-specific treatment is also appreciated [102]. Recommendations state that stroke interventions should focus on self-management [72] and reflect patients' needs [58, 80, 99]. This may require that both the patient and stroke therapist adopt a long-term perspective of rehabilitation and be flexible. Healthcare professionals who pay attention to and support like stroke survivors' autonomy, social connection and hope of recovery may encourage their process of re-engagement in previously valued activities [103]. While being at home seems to motivate patients' engagement in rehabilitation [104], stroke survivors have

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made it clear that they also want to receiving stroke-related information [94, 105], psychological support [106], and physical training [52, 93].

Compliance in goal-setting and instilling priorities may also influence patients' ability to live a meaningful life [15, 73]. Some have suggested that discrepancies between patients and healthcare professionals in goal setting and priority setting should be handled by negotiations and by providing emotional support [52, 54, 93, 107].

## 1.4 Preconceptions and theoretical models

### **International classification of function, disability, and health (ICF)**

The International Classification of Function, Disability, and Health (ICF) is both a classification and coding system of health information [108]. It is also a conceptual model of health and health-related conditions [108]. The conceptual model is adopted by healthcare professionals engaged in stroke rehabilitation and contributes to shared understanding of core concepts, which further helps to structure multidisciplinary communication [109]. The model represents a framework to understand patients' needs, agree upon interventions, and obtain an overview of possible resources in patients' lives [110]. The ICF, however, has been criticised in its conceptualisation for omitting the perspective of the disabled person, and further development of personal factors are warranted in order to improve this system [109, 110].

### **Health and disability**

Occupational therapists and other healthcare professionals involved in stroke rehabilitation in Norway are guided by national guidelines [13] in order to understand health and stroke-related disability and to comply with the ICF [108]. Using the ICF means that two main areas are important to consider for achieving individual health: (1) functioning and disability, and (2) contextual factors. Function and disability cover two areas in which stroke after-effects may occur: (1) body function and structure, and

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(2) activity and participation. Activity is defined as a person's execution of a task or an action. Participation is defined as involvement in life situations. Two qualifiers of activity and participation are pertinent: capacity and performance. Capacity is what a person is able to do in a standardised situation, while performance is what the person actually does in his/her environment. Functioning is the term used to describe any positive aspects, while disability is used to illustrate problems in terms of impairment, limitations, and restrictions. The contextual area of implementing the ICF distinguishes between personal factors and environmental factors, like physical and social environments. Personal factors are not conceptualised, but are considered to be a backdrop for understanding by healthcare professionals [108].

The ICF contributes to our understanding of health by conceptualising health as occupying a continuum, one ranging from a bodily-centred perspective to a perspective comprising health as part of humans' daily life [108]. Health may be thought of as a person's ability to engage in daily activities and to participate in society, which can either be hindered or promoted by individual biological factors, psychological factors, and social factors in that person's life. This is referred to as a bio-psycho-social understanding of health. A possible disability, however, does not necessarily indicate that a disease is present; thus, this view differs from the traditional biomedical view of health and illness as being mutually exclusive [108].

It has been argued, however, that healthcare professionals' understanding of health is still influenced by traditional biomedical ideas [111-113]. These authors point out that this view can be influential in encounters between patients and healthcare workers, in that they see disease and symptoms as pathological problems in individuals. Furthermore, they argue that standardised outcome measures that have been developed to distinguish between healthy and diseased are emphasised predominantly in stroke research. Presently, interventions are directed towards restoration of normal function and especially improving physical disabilities. They also point out a tendency to

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consider healthcare professionals as the ‘only’ experts capable of directing recovery [111-113].

## Salutogenesis

Salutogenesis (latin: salus=health, greek: genesis=origin) encompasses a view of health that includes the concepts of health, stress, and coping, as seen from the perspective of individuals [114]. Health is viewed in this context as a ‘health ease’ to ‘dis ease’ continuum, in which people perceive themselves being more or less healthy. Demanding and stressful situations are seen as challenging but quite normal parts of life. Life experiences affecting core areas in one’s life, like inner feelings, close relationships, valued roles, or matters of existential nature, are hard to ignore and need to be acted on. A person’s ability to cope successfully or not, will affect one’s perception of where they are on this continuum of health. A salutogenetic approach aims to identify determinants of health and is complementary to the more traditional pathogenetic way of thinking about health. The main salutogenetic question is this: What contributes to coping with traumatic life experiences in a way that is good for one’s health [114]?

Antonovsky’s salutogenetic model focuses on two aspects of coping: (1) identifying a Sense of Coherence (SOC), and (2) the ability to mobilise General Resistance Resources [114]. General Resistance Resources are potential resources available in people’s lives that make it easier to deal with life challenges. SOC is defined as, ‘*A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable and explicable (comprehensibility); (2) the resources available to one to meet the demands posed by the stimuli (manageability); and (3) these demands are challenges worthy of investment and engagement (meaningfulness)*’ [114].

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In the salutogenetic model, it is assumed that a strong SOC is favorable for one's health [114]. The key elements of SOC –meaningfulness, comprehensibility, and manageability– have, respectively, a motivational, cognitive, and behavioural component. In moving the coping process forward, meaningfulness is considered to be most important, followed by comprehensibility, and manageability. Having a strong SOC means being motivated to change, understanding what is happening, and to having access to sufficient resources [114].



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## 2. Aims and objectives

The overall aim of this thesis work was to broaden our understanding of different aspects of daily life after stroke in the context of different models of ESD intervention and outpatient rehabilitation. This was undertaken in order to acquire more knowledge of successful follow-up rehabilitation in the municipality and to contribute to a more comprehensive understanding of what it means to live with mild-to-moderate stroke.

By using both quantitative and qualitative methods, the more specific objectives of each study were:

- To compare three models of outpatient rehabilitation: (1) ESD in a day unit, (2) ESD at home, and (3) traditional treatment in the municipality (control group) using the Assessment of Motor and Process Skills (AMPS) as the primary outcome measure and the modified Rankin Scale (mRS) as the secondary outcome measure. It was hypothesised that ESD models would result in superior outcomes regarding change in ADL ability (in terms of performance and independence) during the first 3 months after stroke (Paper 1).
- To explore stroke survivors' experiences of living with mild stroke in the context of ESD and continued rehabilitation at home. In particular, we focused on understanding patient-attributed meanings of their activity and participation in the recovery process at home (Paper 2).
- To explore mild-to-moderate stroke survivors' experience with home rehabilitation after ESD. We focused on understanding patient-attributed meanings of how this type of service contributed to their recovery 6-8 months after returning home (Paper 3).

### 3. Materials and methods

#### Study designs

This thesis derives from the results of three studies (studies 1-3), which were all designed within the context of the larger RCT entitled, ESD Stroke Bergen. This RCT is registered in Clinical Trials.gov (NCT00771771). Details of the protocol have been published [3]. An overview of methodological information for studies 1-3 is presented in Table 1.

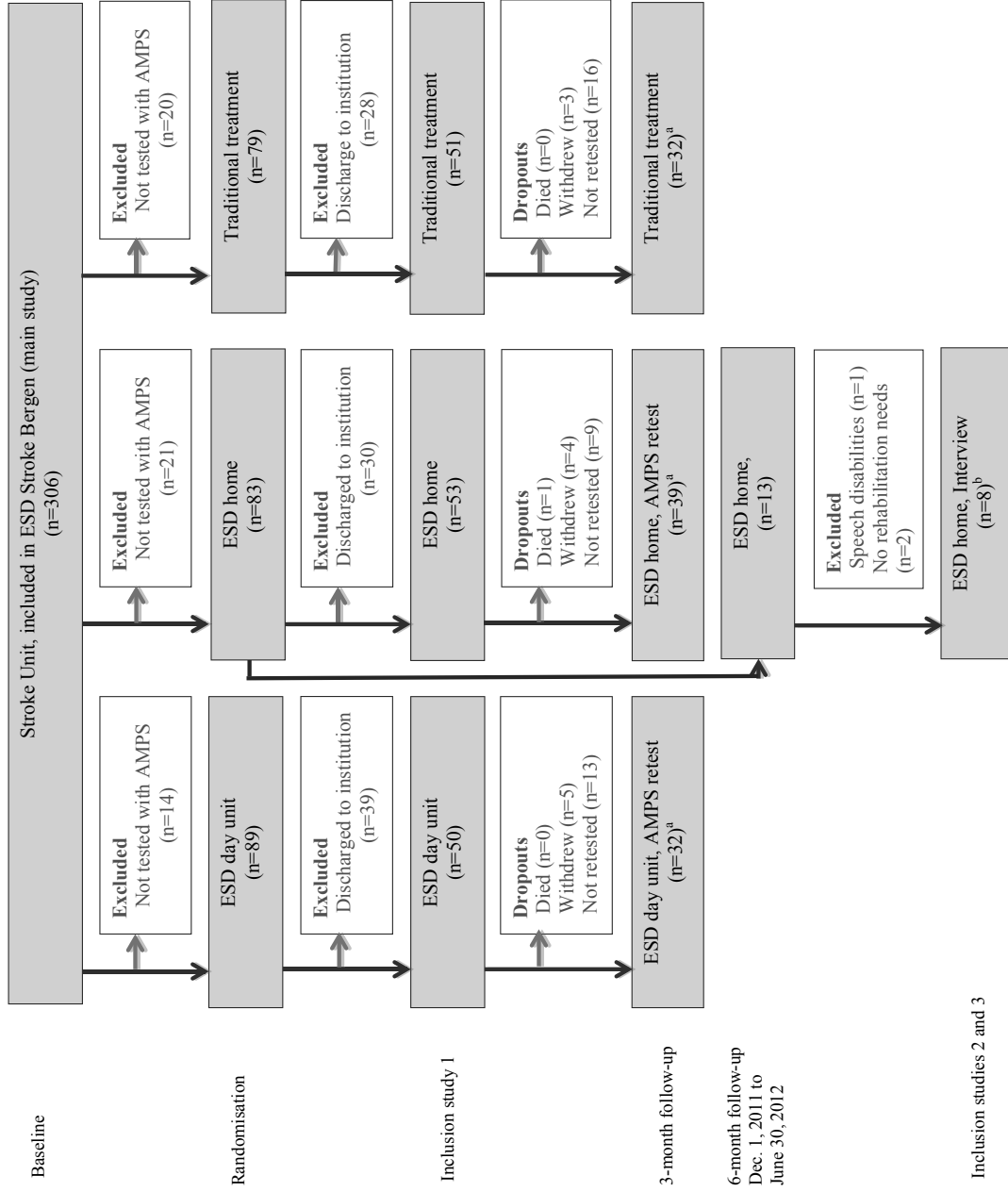
**Table 1.** Overview of the thesis studies organised by design type, selected patient characteristics, primary outcome measures, and types of analyses used

Studies	Designs	Patient characteristics			NIHSS, median (min, max)	Outcome measures	Analyses
		n	Male, n (%)	Age, median (min, max)			
Study 1 (Intervention)	Group comparison within a RCT Longitudinal	154	88 (57)	73 (29, 98)	4.4 (0, 26)	AMPS mRS	Descriptive Independent t-test Mann-Whitney U test Exact Chi-square Paired t-test McNemar's test ANOVA Linear regression Logistic regression
Studies 2 and 3 (Interview)	Interpretive Cross-sectional Retrospective	8	4 (50)	57.5 (44, 80)	3.5 (0, 15)	Qualitative interviews	ID STC SOC

Abbreviations: AMPS, Assessment of Motor and Process Skills; ANOVA, Analysis of Variance; ID, Interpretive description; mRS, modified Rankin Scale; NIHSS, National Institutes of Health Stroke Scale; RCT, Randomised Controlled Trial; SOC, Sense of Coherence; STC, Systematic Text Condensation.

#### Patients

A flow diagram of all stroke patients recruited from the ESD Stroke Bergen and their course through study 1 (intervention study) and the interview studies (studies 2 and 3) is presented in Figure 1



**Figure 1.** Flow diagram of all stroke patients included in the main study (ESD Stroke Bergen), randomised to three different models of stroke rehabilitation: (1) ESD in a day-unit, (2) ESD at home, and (3) traditional rehabilitation. <sup>a</sup>Patients included in study 1, assessed by AMPS at baseline, discharged directly home, and completed the study; retested with AMPS at 3 months. <sup>b</sup>Patients included in studies 2 and 3 randomised to home treatment, invited and responded to 6-month follow-up.

## **Inclusion and exclusion of participants in ESD Stroke Bergen and in studies 1-3**

The inclusion period for the ESD Stroke Bergen RCT was from 8 December 2008 to 20 December 2011[3]. Inclusion criteria for participants were the following: resident of Bergen, living at home, recruited for the study within 6-120 hours after hospitalisation and within 7 days after symptoms onset, obtaining a NIHSS score of 2-26 at inclusion or having an improved mRS score of 2 points if they scored 0 or 1 prior to the stroke, and giving written informed consent themselves or receiving it from responsible relatives. Exclusion criteria were the following: lack of familiarity with the Norwegian language and having serious conditions unrelated directly to stroke but of importance to the cerebral disorder or the process of rehabilitation. This last exclusion criterion would include, for instance, substance abuse or presence of psychiatric disorder(s) [3].

Study 1 (i.e., thesis intervention study) followed the inclusion period for the RCT, but additionally had the following inclusion criteria: having been tested with the AMPS at baseline and been discharged directly to home from the stroke unit.

The inclusion period for studies 2 and 3 (i.e., thesis interview studies) differed from the RCT. It was from 1 December 2011 to 30 June 2012. This difference occurred because of different implementation dates of the interview studies and the RCT. Additional inclusion criteria for studies 2 and 3 were as follows: having been randomly assigned in the RCT to the home rehabilitation group and having been invited and responded to 6-month follow-up. At this time after stroke onset, we reasoned that the participants had gained some experience with living with stroke and with rehabilitation at home and that the experiences from the acute phase of stroke were not foremost in their thoughts and memory.

Patients assigned to home treatment were chosen so that their experiences could inform the research questions, given that there was limited previous knowledge about patients' perspectives on treatment at home. Additional exclusion criteria were the

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following: had speech disabilities that would hamper a conversation; and having no rehabilitation needs after the acute treatment in the stroke unit, and thus, having no experiences to share about the phenomena of interest.

Two patients discharged to an institution before homecoming were not excluded. One patient, who was asked to participate and accepted, was not interviewed because we already had enough data to sufficiently address the aims of the studies. One patient was interviewed but was subsequently excluded from the RCT and therefore, also from these thesis studies.

## Data sources

### **AMPS**

To measure ADL ability, one prerequisite we had was to use outcome measures recommended within the stroke rehabilitation field [13]. Based on promising psychometric qualities, we choose AMPS as the primary outcome measure [91, 115].

The AMPS is a measure of the quality of a person's ADL performance, providing information related to the activity component of the ICF [115]. The construct 'quality of ADL performance' refers to quality of observable skills when performing tasks like opening a door, grasping a tool, or selecting an appropriate sequence of implementation when performing an ADL task. These do not refer to specific body functions, like underlying cognitive or neuromuscular impairments, but rather goal-directed actions needed to perform any ADL tasks. Social aspects are not part of the AMPS. The construct reflects also a person's universal ADL performance, which is the focus of global evaluation methods. On a continuum of evaluation methods from discrete body function measures to global ADL measures, the AMPS instrument occupies a position somewhere in between [115].

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The quality of a person's ADL performance is assessed in terms of defined quality criteria [115]. A raw score is given by observing how effectively, safely and independently a patient performs an ADL task, as well as the degree of effort he or she expends during the performance. The therapist's summed ordinal item scores (i.e., raw scores) are converted by a many-faceted Rasch analyses into equal-interval numbers that can be placed along a common linear scale. This kind of analysis make it possible to take into account that therapists vary in severity of their ratings, ADL tasks vary in difficulty and patients vary in ADL ability. This allows us to compare the outcome among groups of patients who perform different AMPS tasks and of patients who perform different ADL tasks at each time of evaluation. Special challenges related to cognitive limitations, need of assistance, and/or language impairments are discussed in the manual, as are parts of the score calibration procedure. However, clear agreement between the therapist and the patient must be reached [115].

The AMPS provides information on two different scales, one reflecting the patients' motor ability (AMPS motor scale) and one that reflects the patients' process ability (AMPS process scale) [115]. The data are continuous, placed on interval scales ranging from -3 to +4 for the AMPS motor scale and from -4 to +3 for the AMPS process scale. High scores indicate high quality ADL performance, and low scores indicate poor quality ADL performance. Data from AMPS testing are commonly dichotomised in order to discriminate between patients who are independent in ADL and those who are not. The cut-off score for independence is  $\geq 2$  on the AMPS motor scale and  $\geq 1$  on the AMPS process scale [115].

The AMPS is highly reliable for test-retest, inter- and intra-rater rating, and parallel forms of the AMPS are reliable [115-117]. The AMPS also is valid for use in stroke survivors, despite differences in underlying impairments [67, 118], and is valid across genders [119, 120] and age [121]. When using the AMPS in stroke rehabilitation, the best quality ADL performance occurs about 3 months after discharge [60].

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The AMPS is considered to be objective, and no ceiling effect has been reported [115]. Additionally, the sensitivity of the AMPS for detecting changes after rehabilitation seems adequately evaluated and is satisfactory [91].

## **mRS**

The mRS is recommended for assessing a person's global ADL performance after stroke [13]. This means that the mRS provides information related mainly to the activity components of the ICF, but participation restrictions and underlying physical impairments are also captured [122]. Because the mRS is commonly used in stroke research, comparison of study results is possible. Moreover, the psychometrics of the mRS are acceptable [122].

The mRS is scored on a 7-point ordinal scale (0-6) [123]: (0) indicates no disabilities are present, (1) indicates minor physical impairments are present, (2) indicates participation restrictions are present, (3) and (4) indicate ADL limitations are present, (5) indicates severe disabilities are present, and a score of (6) is assigned when the patient is dead. The assigned scores reflect the comparison with the patient's ability level before the stroke. Data from the mRS is commonly dichotomised in order to discriminate between patients who are able to live independently at home and those who are in need of assistance, but no consistent method of dichotomising is available [122]. Since the main outcome in the current study was ADL ability, we chose a cut-off score on the mRS of  $\leq 2$  as the best dichotomisation option.

The mRS is highly reliable and valid when used in stroke survivors [122]. When evaluated in terms of avoiding a ceiling effect, its use may have an advantage over other widely used instruments; information on its sensitivity to change is limited. The mRS has been criticised for being subjective, but use of structured interviews has shown to increase its inter-rater reliability. It is recommended that mRS testing be supplemented with other standardised outcome measures [122].

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## **Qualitative research interview**

The use of qualitative research interview is appropriate when targeting the first-person perspective of for instance patients experiences of living with a chronic condition or their experiences with healthcare [124]; in our case, it is living with the consequences of stroke and experiences with home rehabilitation. As Malterud [125] underscores, qualitative individual interviews are well suited when researchers seek a confident and calm situation that allows patients to open up and share their specific stories about changes and associations. In our case, we sought to better understand the patients' present situation taken from their perspective; also differences in their daily life before and after the stroke, and their desires for the future. We found the phenomena of interest to be well suited for individual interviews.

We used a semi-structured interview guide (Appendix 1), one having a flexible structure and open-ended questions related to the topics of concern [124]. This approach contributed to achieving a balance between encouraging participants to freely share their experiences and the researcher's aim of focusing on the phenomena of interest. A face-to-face situation provided access to non-verbal information also. Facial expressions and bodily posture may reveal emotions related to what is being said and contribute to relational information [124]. This information guided the researcher in how to proceed, for example, when to be quiet and when to change the topic in the interviews.

## **Other data sources**

Background information of participants obtained for this thesis work, including sociodemographics, diagnosis, clinical status, and treatment were retrieved from the ESD Stroke Bergen database. Medical records at admission to the hospital were the source for the sociodemographic data.



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The diagnosis procedure for determining stroke complied with national Norwegian recommendations [13]. Stroke severity was determined by using a Norwegian version of the NIHSS, that included 13 items [8]. Details about treatment provided contextual information for studies 2 and 3. This information was acquired from forms designed specifically for the ESD Stroke Bergen and used by healthcare professionals involved in home and day-unit rehabilitation.

## Procedure

All data for this thesis work were anonymised and data files were stored on the research server at the Haukeland University Hospital.

### **Study 1 - Intervention study**

In study 1, the objective was to compare the change in ADL ability (in terms of performance and independence) during the first 3 months after stroke, assessed in the context of three different models of stroke rehabilitation applied in the municipality. The three models were: (1) ESD followed by home rehabilitation, or (2) ESD followed by day-unit rehabilitation, or (3) ordinary treatment. AMPS scores were our main outcome measure of ADL ability, and mRS scores were a secondary outcome measure.

Baselines tests were given and background information was collected during the initial stay at the hospital after stroke. AMPS administration took about 30 to 45 minutes, and was performed by trained and certified occupational therapists and was done in accordance with the AMPS manual [115]. Our intention was to test all patients who satisfied the inclusion criteria of the ESD Stroke Bergen RCT. For those who were tested, a median of 1 day passed between admission to hospital and administration of the AMPS. The baseline mRS was administered by neurologists or trained stroke nurses. This assessment is based on observation of and conversation with the patient [122], and was guided by the structured interview [123]. It took about

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5-15 minutes to administer. The mRS is intended to be used at the time of discharge [122]. Baseline assessments were performed 7 days after inclusion, or earlier if needed, depending on the time of discharge [3].

Participants were sequentially enrolled in the study by a person who was neither involved in the randomisation process nor involved in the treatment [3]. After baseline testing, the participants were randomly assigned to a treatment group based on a computer-generated list, with 6 participants in each block. The assignment list was known by a study coordinator but not by the person responsible for recruitment [3].

Initial treatment was in a specialised in-hospital stroke unit. All the participants were discharged to their home directly after their initial hospital stay. Due to different medical or practical needs, the length of stay could vary. Patients who transferred to further in-hospital rehabilitation before coming home were excluded from study 1. This situation might occur because severe disabilities were evident or speech therapy was needed, and access to such treatment was limited in the municipality.

For the intervention groups, two multidisciplinary teams were established, a hospital outreach team and a municipal healthcare team [3]. This was done to support the participants and their families during the rehabilitation process. The hospital team was responsible for coordination and planning the homecoming and, therefore, they established contact with the patient during their stay in the hospital. If possible, a visit to the patient's home was also organised before discharge, so that any further needs crucial to early discharge might be revealed. The municipal team was invited to the home visit and a subsequent transfer meeting in order to help coordinate the two levels of healthcare service. Further treatment either at home or in a day unit was the responsibility of the municipal healthcare team [3].

The conceptual model of the ICF was used by the healthcare professionals involved in the ESD rehabilitation, and their treatment plan was guided by national guidelines

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[126]. Additional medical support by a general practitioner (GP), or treatment by other relevant healthcare professionals were provided, if needed [3].

Day-unit rehabilitation meant travelling to a day unit in the municipality and staying there for the day [126]. Treatment was mainly individualised focusing on treating bodily impairment. Indoor and outdoor activities were performed, including preparing a lunch, hiking, and ADL [126].

Treatment at home mainly involved performing task-specific activities in familiar environments, like performing ADLs, or outdoor activities, like travelling by bus, doing gardening, or walking [126]. The amount of treatment was mainly regulated by the kind and severity of after-effects of stroke and the patients' general fitness at the moment. Access to treatment equipment was limited at home [126].

The control group were not followed by the outreach hospital team or the municipal healthcare team [3]. Ordinary treatment in the municipality is usually prescribed and recommended by the healthcare professionals at the hospital stroke unit and guided partly by the patient's scores on physical outcome measures like the mRS [31]. It is up to healthcare professionals in the municipality to decide what amount of rehabilitation is needed, which was probably guided by national guidelines [6].

Face-to-face contact between patients and multidisciplinary groups of professionals representing different healthcare levels is not part of what typically offered to stroke patients in the municipality. Therefore, the treatment was probably less coordinated for the control group than for the intervention groups. Further information about the control group is limited and mainly based on previous experiences of what is offered to stroke survivors in the municipality. Treatment might have been offered in the patients' home or outdoors by an occupational therapist, physiotherapist, or nurse from the home municipality and/or a physiotherapist working in a private physiotherapy clinic. Healthcare professionals would usually make day-to-day decisions as individuals, not as a team.

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Systematic 3-month retest was included in the design of the ESD Stroke Bergen RCT [3]. This interval period also is in line with recommendations for the AMPS [60] and for the mRS [8], indicating that patients' ADL ability likely reaches the highest level at 3 months and remains stable for some time. For retest, we relied on research results, which demonstrate adequate inter-rater reliability [117, 122]. This reliability results in consistency in scoring among raters using the AMPS [117] and the mRS [122], allowing us to confidently use different therapists in patient assessments. In order to standardise the AMPS testing conditions as much as possible, the AMPS retest and the baseline AMPS test were both administered by therapists from the Department of Occupational Therapy, but carried out in two different locations. No special equipment was required for mRS retesting, which was performed either during home visits or at the hospital outpatient clinic by a trained physiotherapist.

## **Studies 2 and 3 - Interview studies**

In studies 2 and 3, the objective was to explore patient-attributed meanings of their activity and participation in the recovery process at home and how this type of service contributed to their recovery 6-8 months after returning home. In order to better understand the experience of recovering from and living with stroke in the context of ESD to home, patients were recruited from the ESD Stroke Bergen RCT. The empirical material from study 2 interviews informed also study 3, focusing on how treatment at home suited their needs. Participants were invited for participation and informed about the study by a person responsible for coordinating the follow-ups at 3 and 6 months. This person was not involved in patient treatment. Those who consented were called by the author of this thesis in order to make an appointment for an interview.

By proposing to conduct the interviews at the patients' homes, we aimed to have a relaxed atmosphere suitable for sharing thoughts freely [124]. However, final decisions about the location were guided by the participants' wishes; thus, 6

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interviews were performed in the participants' home and 2 in a hospital location. One participant chose to have next of kin present during the interview.

The choice of main topics in the interview guide was influenced by previous research, the thesis author's professional concerns about activity limitations after stroke, and discussions with the more experienced supervisor in the qualitative approach (M.R.), and other colleagues. One pilot interview was conducted in order to assess formulations and relevance of the questions. All participants were interviewed once and asked about the same main topics. The order, intensity, and to some extent, the formulation of questions varied depending on the progress of each interview.

Since we were interested in the participants' attributed meanings, the main themes in the interview guide were elaborated on by posing additional follow-up questions created on the spot. This encouraged the participants to expand on their reflections or clarify their statements.

All interviews were conducted and transcribed verbatim by the author of this thesis. Collection of background information of the participants was not tape-recorded but was usually clarified before conducting the main part of the interview. Reflection notes the author prepared immediately after each interview were intended to complement what was captured on audio recordings. The notes contained reflections related to the interaction between the researcher and the participant. This was, for instance, reflections about challenging situations related to role conflicts or emotional reactions on the part of the interviewer and her attitude to what was conveyed, as well as thoughts about practical interview techniques.

Data production ceased when the research material was considered to contain sufficient common features and variety of experiences to address the aims of the studies.

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## Data analysis

### **Statistical data analysis**

Descriptive statistics were used in all the studies to describe characteristics of the included samples and also in study 1 to describe the change in scores of the outcome measures. Means and standard deviations (SD) were calculated for continuous data that had an approximate normal distribution, while median and minimum/maximum scores were used for skewed data and to exclude the influence of outliers. More detailed statistical analysis was only part of study 1.

Parametric tests (independent t-test and Exact Chi-square test) and non-parametric tests (Mann-Whitney U test) were used to compare baseline data between the group of participants who were included in pre- and post-tests and those who were dropouts at post-test. Parametric tests (paired t-test, Exact Chi Square, ANOVA) and non-parametric tests (McNemar's test) were used to compare pre-post changes in outcomes and differences between the intervention groups and controls.

The high dropout rate represented a violation of the randomisation assumptions, making it imperative to control for possible confounding factors. This was done by estimating regression models with the AMPS and the mRS at 3 months as dependent variables and treatment as an independent variable, while adjusting for age, baseline scores of the dependent variables and a number of other variables. A linear model was fitted for the AMPS and mRS scale measures with treatment in two groups (ESD in a day unit and ESD at home in one group [ESD groups] versus traditional treatment [control group]). Logistic regression was used with treatment in three groups (ESD in a day unit and ESD at home as separate groups versus control group)

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## Qualitative analysis

Tape recordings and transcribed text from 8 interviews with 8 participants were included in the qualitative analysis. Reflective notes of this thesis author made immediately after each interview were also part of the material for analysis. Analysis of the transcribed interviews was informed by Interpretive Description (ID), as laid out by Thorne [127].

Qualitative data analysis used in healthcare research is recognised to typically rely on strategies developed within the field of phenomenology, grounded theory, or ethnography, in which theorising is an important basis for knowledge development. In ID, researchers are invited to direct their studies towards practical healthcare issues [127]. Development of knowledge is accomplished by using a research attitude that includes elements from clinical assessment, which are specific and familiar within the scholarship of the practical healthcare disciplines. Using theory in challenge and development of concepts are, however, also welcomed, but in the context of practice related research questions [127].

For healthcare professionals, an initial descriptive approach serves to reveal issues worthy of attention and that take note of the complexity of human experiences. It is also the basis for intellectual curiosity and foundation for new questions that need to be answered. ID welcomes also clinicians' commitment to reflect on associations and patterns by encouraging a mental attitude that seeks possible attributed meanings of what is said, in which context, and how actual experiences may make sense within clinical health practice [127]. This interpretive process is accompanied by the researchers' previous experiences with the phenomena under study and by current research within the field of interest, both of which partly form the basis for questions asked by the researcher. Appropriate theoretical frameworks may be applied in order to further illuminate the empirical knowledge that emerges on the issues under study, and thereby achieves a deeper understanding. Core findings may allow for 'best guesses' of explanations. To avoid premature and predetermined explanations,

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inductive use of a relevant theoretical framework is reserved for later stages of the analytic process. Disciplinary, practical, and theoretical preconceptions that might motivate the study need to be recognised, however, and challenged early on in the analytic process [127].

We decided to include the procedure of systematic text condensation (STC) as an analytic scaffold allows, in addition, a very systematic search for common themes across all interviews and a consideration of a the diversity of nuances within each theme [128]. STC is a step-wise procedure, implying de-contextualisation and re-contextualisation [128].

First, each interview was examined thoroughly to obtain an overall impression of what was at stake for each participant, as well as to ascertain the importance they placed on certain topics and situations. Then the interviews were read transversally to obtain an overall view of the interviews as a whole, noting preliminary themes. De-contextualising involved identification of all meaning units in the text, that were potentially relevant for the research question and taking these out of the transcripts and organising them into codes across all the interviews. The meaning units within each code group were further sorted into sub-codes. The sub-codes represent different aspects of meaning. Re-contextualisation meant considering the findings in light of the larger context of the original text and presenting them in a way that was true to the original text.

Using this step-wise procedure did not mean that the analytic process was linear and strictly sequential. It meant rather that we went back and forth between the different steps. Because we recognised that the data material was abundantly filled with both common patterns and varied descriptions of life after stroke and of how home rehabilitation suited the patients' needs, it led us to believe we could also capture possible underlying meanings of the participants' experiences.



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The participants' stories had a strong presence of emotional concerns about how to deal with the after-effects of stroke. At the same time, aspects of hope and belief in something better seemed important to them. Our focus was on understanding patient-attributed meanings of how daily life was experienced by stroke survivors in the special context of home rehabilitation and how the rehabilitation service contributed to their recovery or hindered it. To deepen our understanding and get a firmer hold on what was going on with them, we reasoned that theories of coping, which are capable of touching upon a more profound aspect of life after stroke, would be an appropriate inspiration.

Antonovsky's salutogenic model of SOC was regarded as being an appropriate frame in helping us to deepen our understanding of the participants' experiences [114]. Using the model made it possible to consider the participants' experiences not only in light of the context of home rehabilitation, but also to focus on their hopes, which seemed vital to them as a driving force. Additionally, SOC helped us to focus on other existential dimensions [114], which also seemed so important for the participants in our study. This inductive way of theorising is in accordance with recommendations in ID [127], providing in-depth understanding suitable for capturing core meanings in the participants' experiences, for better understanding of why the experiences were as they were, and for capturing different nuances of emotional response to stroke. Theorising might also stimulate some explanations about what contributes to coping with chronic conditions, for instance, with the after-effects of stroke.

Qualitative data analysis of the interview material formed the basis for the findings in studies 2 and 3. The analytic process is further detailed in paper 2.

### **Researcher's role and reflexivity**

Reflexivity refers to the process of articulating preconceptions that motivate research, and tacitly implies the research process [129]. The process involves evaluation of the

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researcher's influence on the different steps of designing and carrying out a study, including the data production and data analysis. While Stiege et al. [129] offer a practical tool to prompt important questions to be reflective, reflexivity in the research process entails also a personal and demanding process for the researcher, one that stimulates her to strive to be careful, conscientious, and self-aware about opportunities to discover new perspectives in the research process [130]. During the analytic process, ID encourages a flexible and creative attitude, and allows the researcher to draw inspirations from different analytic methods suited to elucidate the question of interest, or what is feasible related to the quality of the research material [127]. This pragmatic attitude is acknowledged [129], but requires extra demands as to reflexive articulation of the analytic mind-work all through the research process [127].

Recognising the researcher's professional focus on activity and participation and the ICF model [108] providing the underlying assumptions that motivated the study and guiding the understanding of stroke rehabilitation, we believe the relevance of these preconceptions seems important to evaluate. The author of this thesis recognized, however, it as being more like a process, which was increasingly present throughout all the different stages of this thesis work, rather than just at a specific phase of the research process. To avoid rushing to conclusions, and to what Thorne calls 'premature closure' of the analytic process [127], the author of this thesis endeavoured to achieve a prolonged and systematic engagement in the empirical data, continuously trying out different codes and their relevance weighted in different ways throughout the process of becoming acquainted with the overall impression of the interviews. During this process, she actively considered the principle questions from Thorne [127], like 'What am I learning about this?' and 'What is happening here?', These, and other questions, were used to open up her thinking about alternative understandings of the research material. Especially useful were discussions with the more experienced supervisor (M.R.), which contributed to a deeper consideration of the existential perspective of the stroke survivors' experiences. Additionally, and

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during debriefing sections, all the supervisors involved offered insight and questioned truism and the researcher's assumptions that she had taken for granted. Reflexivity notes of the researcher assisted in bringing to the table especially issues that provoked emotional reactions in her, like feeling uncomfortable or disappointed. Again, the questions from Thorne were used together with close interaction with the supervisor (M.R.) to promote reflexivity in the research process. The findings were also shared in qualified forums, which invited open discussions that could help expand on understandings.

## Ethical issues

Ethical principles stated in the Declaration of Helsinki were followed in the conduct of the research for this thesis [131], and all studies (studies 1-3) were approved by the Regional Committee for Medical Research Ethics, Western Norway.

Study 1 was part of the original application of the ESD Stroke Bergen RCT, which was approved by the Regional Committee for Medical Research Ethics (project number 070.08) and also by the Social Science Data Services (project number 18993). Studies 2 and 3 involved collecting new data from a subsample of patients, who were originally included in the ESD Stroke Bergen RCT. A protocol amendment was submitted to the Regional Committee for Medical Research Ethics for studies 2 and 3, which was approved in accordance with the application (reference number 2010/2463-2).

Basic ethical research principles of respect, beneficence, and justice were relevant for this thesis project, as is the case for any research involving humans [132]. In specific research involving vulnerable groups, patient dropouts and sensitive themes need to be discussed.

Suffering stroke or being a close family member to a stroke survivor may mean being in a vulnerable situation. This can arise because of the sudden and overwhelming

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event of the stroke event itself, the ensuing feeling of helplessness when now engaging in activities previously taken for granted, or the new perception of failing to be recognised as the person you want to be.

Although participation in the thesis research was voluntary, it did require written informed consent. For study 1, informed consent could be given by relatives initially after the stroke, because medical reasons might preclude the patient from consenting directly. However, even in this case, we subsequently obtained informed consent directly from the patients as soon as they were able to give consent. For the interviews, all patients gave written informed consent themselves. Informational letters and information provided verbally outlined the participants' right to withdraw from the study at any time and without the need to provide justification. Contact information of the study coordinator and the researcher were given, and the participants could at any time contact the coordinator or the researcher to ask questions about the studies.

Experienced therapists capable of handling unforeseen events were responsible for the AMPS testing. Clinical assessment of the patients' well-being was very important to us, and whether to proceed or not with the AMPS administration was determined by the patients' needs that might be revealed through a systematic conversation prior to the test. AMPS testing were part of the routine in the current stroke unit, and the results were used to inform the course of individual rehabilitation.

Acknowledging that patient dropout must be respected with regard to research ethics, an ethical dilemma arises, too, when dropout contributes to low statistical power of the study. In order to detect a clinically important difference in outcome, the sample size was calculated *a priori* for the primary outcome (i.e., for the mRS) in the larger ESD Stroke Bergen RCT and for the primary outcome (i.e., for the AMPS) of study 1 in this thesis research. However, the sample size actually obtained for study 1 was smaller than what our power analysis recommended for confidently comparing the AMPS results of our three treatment groups.

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Attending to sensitivity of participant feelings was a priority in the interviews. To interview patients about life with illness, after-effects of stroke, and the like imply that touching upon possible sensitive topics is inevitable. Even if the planned main themes and the open questions were considered to be relatively neutral when they were formulated beforehand, an interview situation may end up being unpredictable, and how it unfolds depends largely of what happens at the moment. Furthermore, questions related to the rehabilitation service may bring up memories of treatment or situations the participants were critical about and thus, such questions may be experienced as threatening to share with the researcher. This means that the researcher had the responsibility to act in accordance in this situation with general moral principles, which is imperative in all interpersonal communication [133]. For example, application of this principle meant meeting the participant to be interviewed with respect, openness, and sincerity, in which respect is especially linked to acknowledging the other persons' autonomy and dignity. Despite this acknowledgement, in interview situations, moral principles may be challenging to apply. This may arise, for instance, when encouraging the participants to share details of their private stories in order for the researcher to obtain rich material for analysis. At the same time, the researcher is doing their best to recognise moral boundaries, specifically being aware of and respecting the patients' interests. This might involve avoiding intrusive or explicit questions at the expense of the researchers' interest.

In later phases of the research, the moral principle may be related to the researchers' negotiation between their own interpretive authority and the participants' intended meaning in their conversations. Hearing powerful stories conveyed by persons' living with chronic illness like stroke, emotions will prevail and is a natural part of interpersonal interactions. Emotional reactions on the part of the researcher need to be acknowledged, however, in order to avoid taking over the analytic process [133]. Rather, these emotions need to contribute to strengthening the researchers' understanding of the data [133].

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The benefits of participating in the interviews, however, may have been the participants' opportunity to present their own views and stories related to a changed body, daily activities, and experiences with stroke rehabilitation. The author of this thesis was not involved in treatment or planning the ESD Stroke Bergen RCT, only in the interviews. However, a possible role conflict may come to the fore when the interviewer is both healthcare professional and a researcher [134, 135]. This was realised in the interviews, as the participants were aware of the fact that the researcher also was an occupational therapist.

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## 4. Summary of results

### Paper 1

Taule T, Strand LI, Assmus J, Skouen S. Ability in daily activities after early supported discharge models of stroke rehabilitation. *Scand J Occ Ther* 2015 [accepted for publication 14 April 2015].

We compared three different models of outpatient rehabilitation: (1) ESD in a day unit, (2) ESD at home, and (3) traditional treatment in the municipality (i.e., control treatment). It was hypothesised that ESD models would result in superior outcomes in terms of changed ADL performance or level of independence attained during the first 3 months after stroke.

The study included 154 patients, with a median age of 73 years; 63% were female, the median (min, max) NIHSS score was 4.4 (0, 26). At baseline, scores on the primary outcome measure (AMSP) showed that a majority of patients were dependent in terms of ADL. A minority were dependent in terms of ADL, as shown by scores on the secondary outcome measure (mRS). Approximately 67% (103) of the patients were retested at 3 months (32 from the day unit group, 39 from the home group, and 32 from the control group). Dropout patients were compared to those who completed retesting and were found to be older ( $p=0.003$ ), to live alone more often ( $p=0.008$ ), and to have suffered a more complicated stroke ( $p=0.041$ ).

No significant differences were found when comparing the ESD groups (day unit or home groups) and the control group in pre-post ADL performance or in level of independence, as measured by the AMSP or the mRS. Changed ADL performance and level of independence were significant (for all outcomes,  $p<0.001$ ) within all groups, as measured by the AMPS. No significant changes were found for scores on the mRS scale ( $p=0.063$ ), or for dichotomised mRS scores ( $p=0.077$ ). Controlling for possible confounding factors, we found significant associations for the two ESD

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rehabilitation groups versus the control group in improved ADL performance ( $p=0.027$ ) and level of independence attained ( $p=0.028$ ), as measured by the mRS. At 3 months, we observed for the ESD groups (ESD in a day unit and ESD at home in one group) a significantly greater association with improved ADL performance, than for the control group [ $B(CI)=-0.39(-0.73,0.05)$ ]. For each of the ESD groups, we found a significant greater chance of being classified as independent than for the control group [home:  $OR(CI)=10.45(1.47,74.15)$ , day-unit  $OR(CI)=19.71(1.74,222.63)$ ]. For most models we evaluated, the effect of age was stronger than the effect of treatment.

## Paper 2

Taule T, Råheim M. Life changed existentially: a qualitative study of experiences at 6-8 months after mild stroke. *Disabil Rehabil* 2014, 36(25):2107-19.

In this study, we explored stroke survivors' experiences on how daily life is experienced 6-8 months after mild stroke, in the context of ESD and home rehabilitation. The focus was on understanding patient-attributed meanings of their changed body and daily life in the home recovery process.

The findings offer in-depth insight into mild stroke survivors' 'world' while recovering at home, and showed the ways in which life changed, the challenges they faced, and their thoughts about the future.

We found that existential aspects of life had changed over the 6-8 months after stroke. Experienced changes were related to self-perceived health, the body, self-perception, practical activities, and taking part in social activities. The stroke survivors struggled to make sense of vital health implications of stroke and feared that questions related to life and death might remain unanswered. Bodily changes after the stroke were bothersome to get familiar with, and it was frightening for them when basic bodily functions could not be trusted. A dramatic change in self-esteem



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and perception of being less capable than before the stroke were recurrent themes in the participants' stories. Wondering if they were still good enough as the person they had become after the stroke, being confronted with bodily limitations in daily activities, and living with unresolved health issues meant uncertainty and concerns. This, in turn, complicated their daily life and especially their relationships with important others. It was a painful lesson for participants when limitations emerged and life no longer matched their concept of 'the good life' and what they had hoped for in the future. Unresolved rehabilitation needs were still present 6-8 months after stroke.

## Paper 3

Tina Taule, Liv Inger Strand, Jan Sture Skouen and Målfrid Råheim. Striving for a life worth living: stroke survivors' experiences of home rehabilitation. *Scand J Caring Sci*; 2015, Feb 4

In this study, we explored mild-to-moderate stroke survivors' experiences with home rehabilitation after ESD. Our main focus was on patient-attributed meanings of how this type of service contributed to their recovery 6-8 months after returning home.

The findings offer insight into patients' experience of healthcare professionals' attitudes and actions, what type of competence they need to possess, as well as obstacles in the relationship between patients and healthcare professionals. The findings also offer insight into mild-to-moderate stroke survivors' emotional and existential challenges arising from bodily changes while being engaged in home rehabilitation.

We found that the process of recovery was motivated by a hope of a life worth living. Crucial to their hope was making sense of their now-altered body and emotional reactions, as well as cultivating mutual confidence in the healthcare professionals with whom they were involved. The mild-to-moderate stroke survivors' hope was

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targeted at being able to do at least some of what they had appreciated to do before the stroke. Maintaining hope was also vulnerable in relations between patients and healthcare professionals, who were given a crucial role in guiding the participants' bodily recovery and for what they should dare to hope. In interpersonal relations, the healthcare workers' professional competence, as well as individual ways of communicating and behaving contributed to mutual confidence or failure to do so.

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## 5. Discussion

### Methodological considerations

#### Study 1 - Intervention study

At baseline, 306 stroke survivors were included in the main RCT study (i.e., ESD Stroke Bergen). Of these, 55 patients had missing AMPS scores; therefore, 251 patients were eligible for inclusion in study 1 for this thesis research.

Administration of the AMPS often required transfer of patients between hospital departments. Also, the test procedure was relatively time consuming (about 15 minutes per ADL task x 2). Together, this might have been too demanding and difficult to implement for less able stroke survivors. Further exploration of the performance of those not tested with the AMPS showed they had high baseline mRS scores (median [min, max] of 4 [0, 5]) compared to the mRS scores (median [min, max] of 2 [0, 5]) for those patients that were tested with the AMPS. This indicates there are practical limitations when using the AMPS to assess severely disabled stroke survivors. We did have a relatively large number of baseline AMPS tests available, however, compared to the number of AMPS tests available for stroke survivors included in other RCTs [136, 137].

To eliminate non-experimental factors that could influence the differences in change between the groups –other than the post-discharge intervention– all patients who were discharged to an institution before going home were excluded (n=97). We believe this was a reasonable step, since they could have received therapy there, and including them could have masked the effects of our ESD intervention.

Preliminary analyses showed, as expected, that the baseline characteristics of stroke severity ( $p < 0.001$ ) and ADL ability (for all outcomes  $p \leq 0.001$ ) were in favour of those who were discharged directly home, supporting the assumption that ESD to

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home primarily suits mild-to-moderate stroke survivors [1]. Those discharged home were also younger ( $p=0.020$ ) and a higher proportion lived with a partner ( $p=0.005$ ).

Altogether, 50% of the patients who were included in the main study (i.e., ESD Stroke Bergen RCT) were excluded from the current sub-study. This means that study 1 cannot be defined as an RCT [138], but rather a group comparison study within an RCT.

Even if study 1 was a non-stratified sub-study of patients tested with the AMPS and discharged directly home, a homogenous distribution in baseline characteristics were shown between the intervention groups and control group, suggesting that the treatment groups were comparable. The use of blinded test administrators also strengthens the current study. In clinical intervention studies, however, it is nearly impossible to hide the intervention from the participants or healthcare professionals involved in the treatment. Limited information about content and amount of treatment for the controls is a limitation of the current study, thereby complicating interpretation of results. The widespread use of clinical guidelines within stroke rehabilitation suggests, however, that the participants in all three groups were provided high-quality treatment.

We experienced a large number of dropout patients from baseline assessment to the 3-month follow-up ( $n=51$ ). An initial pilot study might have disclosed that many of those lost to retesting were old, lived alone, and suffered a complicated stroke. This knowledge might have led to a better strategy for adapting data collection to their special needs [139]. The number of dropouts from the different treatment groups (day unit=18; home=14; traditional treatment [i.e., control group]=19) did not differ significantly ( $p=0.083$ ), indicating that the groups were still comparable.

Furthermore, comparing the baseline variables of the patients in study 1 revealed no differences between the groups. However, the unanticipated, relatively low number of patients available for testing led to further considerations.

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With the relatively high dropout rate and relatively large number of excluded patients, we were unable to achieve the suggested sample size of 64, calculated for each group to reach a statistical power of 80%. The sample size power calculation for the main study (ESD stroke Bergen RCT) was based on a different outcome measure [3]; this might also explain the lack of statistical strength in study 1.

Additionally, it seems important to be aware of that using the AMPS means a 20% risk that one of the two tasks performed by the patient is markedly worse or better ( $\pm 0.5$  logit) than the other [115]. This is mainly associated with executing an ADL task that is either too easy or too difficult, or, to some extent, is associated with a real day-to-day variation or random variation. In such cases, having the patient perform a third task would be in accordance with the AMPS manual [115].

Our use of two different hospital environments for the pre-post AMSP test is perhaps the greatest concern with respect to measurement error. As previous research on the impact of different environments on test and retest is limited and did not examine stroke survivors [115], the consequence of our pragmatic choice is unclear at this time. However, about 80% of paired ADL ability measures are –as described in the AMPS manual– estimated to remain stable between two different settings (home and clinical), and any possible difference might favour the home setting. By using different therapists in administering pre- and post- AMPS tests, we exploited the fact that 95% of all raters certified for the AMPS have demonstrated adequate goodness of fit in the many-faceted Rasch model [115].

The AMPS scale has not been reported previously to have a ceiling effect [115]. In general a ceiling effect is considered to be absent when less than 15% of the respondents, in a sample of 50 patients, achieve the highest possible score [140]. In study 1, no participant achieved the highest possible score, neither on the AMPS motor nor the AMPS process scales, which suggests the lack of ceiling effect also in our study. Moreover, some have argued that a significant change is present when the top score (AMPS motor=4, AMPS process=3) minus 2 standard errors (SE) (0.5

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AMPS motor, 0.4 AMPS process) occurs [115]. In study 1 of this thesis research, most patients (n=152) scored, at baseline, below 3.5 on the motor part of the AMSP (AMPS motor) and all patients scored below 2.6 on the process part of the AMPS (AMPS process). This likely indicates that the performance of almost all of the participants was not bumping up against a ceiling, and thus, an improvement could potentially be detected using the AMPS. Significant pre-post within-group improvements observed in our study seem to confirm the benefits of the AMPS scales in capturing change [91].

The mRS scale has not been shown previously to have a ceiling effect, even 29 days after stroke [141]. In our sample of 154 patients, supplementary analysis showed that only 7% of the participants scored in the top end of the scale at baseline, which is acceptable for avoiding ceiling effect [140]. The pre-post change of one score on the ordinal scale, which is generally considered to be clinically significant, was thus possible for most of the participants [122]. In study 1, for example, the between-groups comparison showed a clinically important change for the home group, but no significant difference in change for the entire group on the mRS scale, indicating a limited sensitivity for detecting change. However, we observed a slightly improved mRS score in the ESD groups, but it was not statistically significant. Even if previous studies failed to show a clear ceiling effect for the mRS, information is limited and further research is warranted [122].

Limited sensitivity to change is, however, a general problem for ordinal global measures such as the mRS, which represents broad categories of ADL performance [115, 141]. Another explanation for failing to detect a change is the high variability shown for inter-rater reliability (kappa between 0.25 and 0.74), which might be due to the raters' subjective assessment [122]. In order to strengthen the inter-rater agreement as much as possible, all raters were trained [3], and a structured interview guided their assessment [123]

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The dichotomised AMPS adequately discriminates between stroke survivors in need of assistance and those who are able to live independently in the community (AMPS motor: area under the Receiver Operating Characteristic (ROC) curve=0.8; AMPS process: area under the ROC curve=0.8) [142]. This is in line with new and stringent validation criteria requiring an ROC area under the curve of at least 0.7 [140]. A matched decision between the AMPS motor and the AMPS process, like the AMPS total used in study 1, has highest discriminating power between patients who are able to live independently in the community and those in need of assistance (sensitivity=0.85, specificity=0.83) [142]. This was the case for a sample of patients with different diagnoses, including stroke survivors, indicating that by using the AMPS total, a high percentage of patients (85% and 83%, respectively) are correctly identified as dependent or independent in ADL [142].

A large discrepancy was found when comparing the proportion of dependent participants at baseline, as measured by the AMPS total and the mRS (70% vs. 19%, respectively). Beyond an expectation that some improvement occurred during the time between the two tests [143], this discrepancy might be due to the use of different quality indicators by the two tests. While the AMPS is an observation of patients' ADL performance according to defined quality criteria, the mRS score is given by using patients' pre-stroke ability as a norm. The high proportion of independent patients identified by the mRS indicates that a ceiling effect was introduced by using the dichotomised score. A cut-off score of  $\leq 2$  has been suggested as being optimal (area under the curve=0.96, sensitivity=0.91, specificity=0.98) for stroke survivors with some ADL challenges (i.e., those having a Barthel Index score = 90). Since relatively mildly affected stroke survivors were participants in study 1 and since only 4% of them improved their level of independence attained after stroke, using a cut-off score of  $\leq 1$  might have made it easier to detect an improvement (i.e., prevent presence of a ceiling effect) [122].

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A wide range of analyses were used to investigate the research questions in study 1, increasing the risk of falsely detecting an effect that was not really present (type I error). A Bonferroni correction to adjust the p-value according to the number of hypotheses may have reduced the risk of type I error. Also, an increased risk of failing to detect an effect that is present (type II error) was present in study 1 due to the limited sample size and thus low power.

### **Studies 2 and 3 - Interview studies**

Evaluating the quality of interview studies, in general, requires open dialogue and transparent reflection, so readers can follow the decisions made by the authors and determine whether the decisions are supported by the data [127]. It is also important that knowledge claims are well founded. In this respect quality criteria –which researchers in the field of qualitative research can agree upon to a certain extent– should be discussed in the context of this thesis. For this purpose, the evaluation agenda of Stige et al. [129] are appropriate.

Conducting studies 2 and 3 in the context of a larger RCT (ESD Stroke Bergen) along with combining the methodology of Interpretive Description (ID) with Systematic Text Condensation (STC) require special attention related to the study design we used. The RCT with its sub-studies was primarily designed to illuminate different aspects of the ICF, targeting knowledge based on standardised outcome measures [3]. It was expected from the Department of Occupational Therapy that aspects of activity and participation would be core dimensions of interest. This was in line with the first author's adopted theoretical framework and disciplinary understanding of stroke rehabilitation at that point. This would, however, be a possible limitation of what could be captured in the participants' stories. Adding research questions widened the focus of the interviews (see below). A prolonged and systematic engagement with the empirical data and debriefing sessions with the supervisor (M.R.) contributed to the author's emerging understanding of existential challenges and emotional trauma



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following a changed body after stroke. These aspects were a major concern of the individual participants and at least as important as the performance of activities.

The sub-themes presented in study 2 have some similarities with the structure of the ICF, indicating that preconceptions and disciplinary lenses are well established and difficult to discard. We will argue that this theoretical model is relevant when it comes to sorting out the participants' stories about activities and tasks, taking part in social activities, and so forth. However, this model fell short in helping us to 'see' the existential depth of the patients' struggle to re-establish their sense of self and a life worth living. To do so, we needed to sharpen our senses when listening to the participants and when reading the interview transcripts and turn to other more relevant theoretical perspectives. ICF may both have helped and limited studies 2 and 3. Realising this, we attempted to communicate the theoretical scaffold and preconceptions that we were aware of as openly as possible. A discussion of some background information about our decisions is relevant here, then.

In line with the overall objective of the larger RCT (i.e., ESD Stroke Bergen), the interviews initially intended to identify concrete obstacles that stroke survivors encounter when performing daily activities. This would probably have produced data suitable for a simpler thematic content analysis, in which we planned to rely on STC [128]. Based on the literature we read during the early phase of this thesis work, we gradually got the impression that the ADL-related challenges that mild-to-moderate stroke survivors experience are not as severe as we first thought [31]. Still, little is known about the first person perspective of ESD [15-17].

This discrepancy between the initial aim of the RCT and the need to know more about 'real world' problems from the patients' perspectives, prompted us to design questions capable of capturing stroke survivors' experiences of any given situation as a whole. Furthermore, the initial interviews revealed a complexity of experiences that reached into the existential level of stroke survivors' lives; this seemed essential to explore, also. Thus, the interviews had the potential of serving as the basis for in-

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depth analysis of the participants' experiences. We became convinced about the potential for transforming data into a higher and richer level than one dealing only with conceptual descriptions [144]. On the other hand, the RCT context, to some extent, prevented us from deriving new theories or capturing the depth of some phenomena that we could have explored more [145].

In our search for an appropriate research design, we discovered the ID approach [127]. According to Sandelowsky and Barroso, ID is placed somewhere in a grey zone between interpretive explanations and conceptual/thematic descriptions [144]. The interpretive aspect, however, is criticised for being vague, and a possible tension between description and interpretation is argued [146]. Thus, it became important to clarify our intention of seeking common patterns and nuances in the phenomena that were described and interpreted in our data in order to achieve new insight with respect to our aims of interest. Furthermore, the knowledge claims are communicated in such a way that they can be utilised within the field of stroke rehabilitation. Pragmatic validity is of importance in this context [127, 147]. Incorporating a theoretical framework in the interpretive process was done in order to exploit and push the limits of the interpretive potential of ID, an approach that is encouraged [146].

In planning who would best inform our research question, we intended to let the empirical material reflect different kinds of perspectives moulded by the experiences and circumstances of stroke survivors. Thus, our thought was to interview participants who differed in age, gender, employment status, educational level attained, and stroke severity. By conducting the study within the larger RCT, we became 'victims', in a sense, of the main study (ESD Stroke Bergen). This meant that we ended up with a convenience sample of patients, who were relatively mildly affected by stroke. Consequently, we had to sharpen our initial focus on patients with varying degrees of stroke severity, to one that now pointed to mild-to-moderate stroke survivors, in particular. Although a convenience sample may make it difficult

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to justify in-depth analysis [127], we found that the empirical material provided in-depth information from different individuals that revealed both essentially different and common perspectives, which in the end strengthened the findings of studies 2 and 3.

The participants were invited to participate in the study by a person involved in the RCT and were interviewed by a healthcare professional. This might have influenced what the participants said during the interviews and what they felt they could talk about truthfully and freely. The literature emphasises, for instance, that participants' perceptions of interviewers –including her professional role– can influence interactions during the interview and hence the information that is revealed [134, 135]. Those interviewed in the present studies were aware that the researcher was an occupational therapist and that she was not part of the institution responsible for their care. However, during the interviews, the researcher found it challenging in some situations to balance her roles as a researcher and clinician, especially in cases in which participants needed healthcare interventions.

We used a variety of strategies to make it easier for participants to openly express their experiences, both positive and negative ones. These included asking open-ended questions, especially about their experience with the treatment given; letting the participants choose their preferred interview arena; and allowing their spouse to be present during the interviews. This way, the interviews encouraged varied and nuanced experiences to emerge that might have escaped notice in other studies conducted in the context of ESD.

The participants shared also what seemed to be at stake in their lives. Several gave the impression that they were sharing such information for the first time, indicating that they trusted the interviewer. Some experiences were of a sensitive and private nature, and their relevance to the research question was therefore carefully considered. In interviews with participants that suffer from stroke and other chronic conditions, sensitive matters will arise; thus it is important to protect the participants

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autonomy and dignity [133]. During the interviews, the interviewer became aware of information related to third parties, who had not consented to contribute to the data and aware of information not commonly shared among strangers.

Decisions made by the researcher in the interviews were also influenced by the participants explicitly stating and genuinely wishing for others to benefit from their experiences. In conversations with the participants, however, some stories made a greater impression than others. For example, it was emotionally painful to follow a grandfather's longing for contact with his grandchild, and a worker's struggle to maintain his previous role as a skilled and respected employee. The first author's limited experience with stroke survivors may have made her more sensitive to the emotional aspect of the stories, whereas the experience of supervisor (M.R.) may have made the researcher more conscious of emotional reactions and may have prompted continual and systematic reflections. The finding of a core theme that synthesised the sub-themes was present in all the participants' stories, who also give voice to the diversity of perspectives that are represented there.

The empirical material for studies 2 and 3 came from 8 interviews of 8 participants, which in the 'quantitative world' of clinical research, is considered small. However, obtaining data and analysing it in the context of qualitative interview design enable us to continuously assess of the empirical material according to the research question [127]. After 8 interviews, we assessed the material and determined it was sufficiently rich to illuminate the common experiences of participants, as well as any important differences. This informed our decision to not interview the last patient who agreed to participate in our study. Dealing with interesting stories, piquing our curiosity, it seems tempting to include also this patient in our sample, and surely we could have chosen to do so. At that time, however, the data comprised varied and nuanced descriptions of how it is to live with mild stroke and of the interactions between stroke survivors and those involved in their rehabilitation, information that was not

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previously reported in other ESD studies. Thus, we considered the empirical material from the 8 participants to be sufficient to answer the research questions of interest.

The recommendation to illuminate the research question from different perspectives is from Thorne [127]. For practical reasons, at time, we were unable to take advantage of other data sources or repeatedly engage with the participants. It is likely that interviews of the healthcare professionals who were directly involved in the home rehabilitation would have further expanded our understanding of stroke survivors daily life. This might also have contributed to more suggestions for improvements regarding the treatment given.

To ensure the best possible interpretation of our findings, we presented our findings in qualified forums and encouraged discussion. These discussions encouraged us to implement ideas from recovery to our understanding of rehabilitation [111, 113], for instance, considering the possibility of an increased awareness of the process of adapting to a new self despite being disabled by stroke.

We used a relatively unknown methodology in our research. Because ID is rarely used in our research field, we received interesting responses from our colleagues, ranging from curiosity to scepticism. The additional use of methods and techniques well known in other fields of health research has been questioned. ID [127] guided but did not govern our decision to supplement our analyses with STC [128] in order to ensure that the analytic process was systematic and thorough. We have to clarify that ID and Malterud's method of analysis both represent a pragmatic stance [127, 128]. Neither complies with the strong traditions of, for example phenomenology, ethnography, grounded theory, etc., in governing what sort of research questions should be asked. Both are placed within an interpretive context that invites one to ask research questions relevant to clinical practice [127, 128].

Although ID aims towards in-depth analysis, it does not provide a 'recipe' for how to proceed in the analysis of data [127]. STC, on the other hand, offers a step-wise

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procedure [128]. Even so, we experienced the analytic process to be dynamic rather than sequential, going back and forth between de-contextualising and re-contextualising. To avoid the risk of what Thorne call ‘method slurring’, we used coherent logic when designing the study through the implementation and presentation of findings. Our intent was to justify our methodological decisions as far as possible. Other have suggested that we clarify the links between ID and other methodologies by explicitly identifying the origin of ‘borrowed’ procedures and techniques [146].

One positive aspect of ID is that it requires researchers to be aware of any influence of preconceptions (i.e., disciplinary lenses and theoretical scaffold) during the analytic process [146]. This strengthens a study. Reflexivity on the part of the researcher, however, is widely discussed in the methodology literature in qualitative research, in general and is part of essential quality criteria [130].

The recommendation to spend more time considering the empirical material played an important role in our decision to reserve the theorising to later phases of the analytic process. Even if this way of theorising is argued to be inductive, we realise that existing knowledge from the field of rehabilitation and disciplinary perspectives may have influenced not only the interpretive process, but also the choice to apply SOC. SOC, a component of health promotion theories [114], is now well known within the field of stroke rehabilitation. There are other theories on coping as well that do not focus on existential aspects of recovery to the same extent, or on health rather than disease. Using Antonovsky’s theory of SOC [114] did allow us to explore more in-depth existential dimensions of living as stroke survivors, and to come up with some explanations about why even mild stroke seems so hard to deal with. We could have interpreted the participants’ bodily experiences in more depth. Indeed, an explicit phenomenological stance (i.e., the perspective of the lived body) could have enriched our understanding of these findings, which are only slightly touched upon in the published articles (paper 2 and 3) derived from this thesis work.

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During the analytic process, we realised that the empirical material consisted of first-person perspectives: not only perspectives of living with mild stroke but also of experiences related to home rehabilitation. In the face of such rich material and the fact that the experiences of stroke survivors in the context of ESD and home rehabilitation seemed to have been explored so meagrely to this point, we decided to put an initially planned methodological study on hold. Instead, we examined more thoroughly the participants' experiences, the findings of which are presented in two different papers (paper 2 and 3).

Using ID in research has an explicit goal of generating knowledge of individuals' experiences relevant for clinical health practice [127]. This makes the question of analytic and pragmatic transferability especially relevant to the qualitative studies in this thesis work. Analytic transferability puts the responsibility on the researcher to clarify the logic of the findings derived from the empirical material, and to determine reasonably to what extent the findings of a specific study can be transferred to other relevant settings and patients [147]. For this thesis, we have descriptions that reflect individual and particular experiences, as well as core meanings from the analysis that transcend the individual examples in the findings. The core meanings were interpreted in light of SOC theory, which can permit analytic transferability. Transferability, however, must also be judged by the readers [147]. Reader-based analytic transferability requires that readers consider whether the analytic logic is coherent and the contextual descriptions are specific and rich enough to determine whether the findings are relevant to situations of interest [147]. Relevance of the theory used to deepen one's understanding also comes into play in reader-based judgements.

Pragmatic transferability is related to the usefulness of the findings, and hence evaluating the findings as relevant within a practical health-related context [127]. Pragmatic transferability has to be judged by mild-to-moderate stroke survivors themselves and by healthcare professionals involved in ESD and stroke rehabilitation.

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Still, there is a need for caution when applying our findings to other stroke rehabilitation contexts. For example, young stroke survivors would have different concerns than older ones. As with our participants, who were relatively young, they were concerned with how to fulfil their parenting duties, or their role as an employee. These responsibilities are probably less important for individuals who suffer stroke later in life.

Except from what was available for analysis in the interviews, we had no access to information about the participants' cognitive function or possible fatigue, information that probably would have been helpful in interpreting our findings. Conducting a study within the framework of the RCT (ESD Stroke Bergen) required a maximum of 5 weeks of treatment for our sample. Even if the participants later were referred for further treatment in the municipality, if needed, the treatment time frame of 5 weeks might have contributed to their impressions of home rehabilitation as lacking flexibility.

## Discussion of findings

### **Main findings**

The overall aim of the three studies was to expand our knowledge and understanding of stroke rehabilitation and ESD intervention in different aspects of daily life. Specifically, we wanted to better understand what contributes to successful follow-up rehabilitation in the municipality and what it means for stroke survivors to live with mild-to-moderate stroke. These aims were realised through use of standardised outcome measures in the context of different models of ESD interventions, and through interviews with patients who had received rehabilitation in their own homes.

Differences in pre- and post-stroke ADL ability were investigated in the intervention study (study 1), and the results contributed to knowledge about the 'doing' aspect of daily life. In the interview studies, we explored the patients attributed meaning of



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their activity and participation in the home recovery process in the context of how they experienced their situation 6-8 months after stroke (study 2). We also explored how ESD followed by home rehabilitation contributed to their recovery (study 3). Studies 2 and 3 highlighted knowledge about existential aspects of stroke survivors' daily life and the professional helpers' contribution to the recovery process, as seen from the stroke survivors' perspective.

We found no differences in pre- and post-stroke ADL ability between the intervention groups after the first 3 months of rehabilitation. Unfortunately, study 1 lacked sufficient statistical strength to make clear, unequivocal recommendations for choosing one treatment scheme over another. This lack of a difference between the rehabilitation groups may indicate that addressing the 'doing' aspect of daily life after stroke was sufficiently done in all three rehabilitation schemes. The primary outcome, did also measure significant pre-post improvement for all treatment groups, suggesting that all three rehabilitation schemes can be successful. An alternative explanation is that improvement would have occurred with sufficient passage of time, regardless of treatment after stroke.

Although all three schemes produced similar results with regard to the primary outcome, the interviews did reveal that stroke is a threat to existential aspects of the participants' daily life 6-8 months after onset. This included changes in perception of self and self-esteem and the need of belonging in valued relationships (study 2). Stroke patients gave healthcare professionals a crucial role in their gaining a hope of a life worth living and who they were to become (studies 3). However, in the end, our results suggest that the rehabilitation scheme of ESD and follow-up rehabilitation at home are not suited to fully capture the existential aspects of the participants' daily life after stroke.

One possible explanation for a lack of sensitivity of ESD programmes in completely capturing existential aspect of the participants' daily life after stroke may be found in previous research on fundamental concepts and preconditions that relate to successful

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rehabilitation intervention. This research points out that a shared understanding between stakeholders in rehabilitation of underlying concepts and preconditions governing rehabilitation intervention is a prerequisite for integrated action to be realised [110]. This means that attention should be focused on the ICF [108]. Based on our findings, further success of ESD and follow-up rehabilitation in the municipality seems to depend on healthcare professional's ability to understand mild-to-moderate stroke survivors' existential challenges and emotional strain. In order to better understand this aspect of patients' daily lives, we used the electronic ICF browser [148], realising that existential dimensions are not part of the ICF vocabulary.

Understanding emotion, in light of the ICF and by using the electronic ICF browser, involves two options. One option is to address emotion as part of the body, considering it to be a mental function that can be objectively assessed by healthcare professionals [148]. For instance, by making decisions about whether emotions in a given situation are appropriate. Intuitively, such an approach does not seem suitable for understanding the participants' experiences. Our participants' stories about emotional and existential struggles are based on their experience of a changed body, followed by a changed self, and changed access to others and a practical world, an observation also highlighted in previous research [36, 49-51]. Emotions, in this respect, are fundamentally bodily based and expressed and cannot be reduced to simply an aspect of mental function.

The second option is that emotion is part of the activity and participation component of the ICF [148]. This view requires healthcare professionals to understand emotional concerns in light of interpersonal interaction, one need to focus on individuals' ability to behave in a socially appropriate manner. This view omits the perspective of the disabled person, a limitation of the ICF pointed out previously [110].

Additionally, two pragmatic solutions have also been introduced in previous research [109]. Either of the components of ICF may be expanded to include a subjective

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frame, which has already been suggested for the aspect of belonging [149], or the subjective experience may be integrated in the component of personal factors [150]. Even if a step-wise development of personal factors is planned for the future, the component of personal factors is not yet conceptualised [150]. As a point of departure, it has been suggested that rehabilitation may focus more on stroke survivors' needs [110]. We have suggested that emotional and existential challenges are areas for which healthcare professionals need to pay more attention. Using the ICF is not straightforward, and it seems to involve a risk of neglecting significant aspects of what is important to the patient in daily life.

The ICF may also be used to understand what may increase or optimise the patients' capacity in daily life [110]. This involves an assessment of what the participants actually do (i.e., performance) compared to qualifiers given by a norm (i.e., capacity) [108]. Today, it is highly recommended to assess ADL performances using standardised instruments [35]. Our findings in study 1 show that patients had high scores on the AMPS and the mRS, indicating that they were capable in their ADL performance. The knowledge gained by using standardised measures allows healthcare professionals to distinguish between patients who are ill and in need of further rehabilitation from those who are healthy enough to live independently in the community. Consequently, successful rehabilitation strategies are moving towards restoring normal function. The bio-psycho-social understanding of health seems to promote a model that focuses on disease and symptoms, as well as promoting a distinction between health and illness. This is in contrast to our core finding that stroke survivors strive for a life worth living (study 3), indicating what is important in patients' lives, namely their need to make their best out of the situation. These desires are intertwined with the resources available for help.

Our findings are more in line with a salutogenetic understanding of health [114]. Previous research has pointed out that a possible tension exist between the bio-medical understanding of rehabilitation, in which healthcare workers are socialised,

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and stroke survivors' need to especially address emotional and existential challenges after stroke [49-52, 54, 76, 77, 79]. For the participants in our study, this tension was present, despite suffering 'only' a mild-to-moderate stroke; and that they were independent in terms of ADL. The challenges uncovered, which are further detailed in study 2, are consistent with previous research suggesting mild-to-moderate stroke survivors feel insufficiently recovered [36, 50, 52, 77, 81, 82]. Together, this research indicates that full recovery is not the case for a substantial proportion of mild-to-moderate stroke survivors, also not for those who are assessed as being independent in terms of ADL. We showed that this is also the case within the framework of ESD and follow-up rehabilitation at home.

Achieving a partnership between healthcare professionals and stroke survivors is another valued goal of stroke rehabilitation [6]. The notion of gaining partnership in this context has been criticised for being limited to goal-setting and shared decision making between healthcare professionals and patients. Stroke survivors, however, also desire mutuality in rehabilitation collaborations and for healthcare professionals to have an attitude that acknowledges the experience of the patient [65, 99]. They also want an intervention that targets achieving self-management [72]. Self-management as an ideal is somewhat presupposed in our studies.

During the analysis, we discovered that existential aspects of the participants' experiences dominated their stories. Using the salutogenic coping theory, we discovered that hope and comprehensibility emerged as participants' personal coping resources. These needed to be strengthened and thereby enable self-management. Realising that notions of rehabilitation may be ambiguously understood [99] and that the ICF and commonly used outcome measures in ADL have serious limitations in capturing what is perceived as important to stroke survivors [84, 85], we began to see a need to expand the theoretical framework of stroke rehabilitation. Our suggestion is to incorporate ideas from the recovery literature, which has also been proposed in previous research reports [54, 99]. This may involve acknowledging stroke survivors'

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emotional and existential needs, the experiences of those who suffer from stroke, and the long-lasting process of acceptance. It may also involve acknowledging stroke survivors' adaptations and their need to address not only what should be done in interventions but also how it is done [111-114].

### **Specific findings of study 1- Intervention study**

Stroke survivors included in study 1 had a mean AMPS motor score at baseline of 1.4 (SD=1.0), and 20% of our sample scored above 2.3 out of a possible maximum of 4.0. On the basis of other studies of stroke survivors, we would have expected only about 5% performing at this level [118], indicating that our population has superior motor skills at baseline. Indeed the range of performance in our survivors was -2.12 to 3.99 out of a possible low of -3.0 and high of 4.0, again reinforcing the impression that this group of stroke survivors performed, in general, more towards the able end of motor ADL performance. This outcome was not surprising to us, as ESD is believed to be particularly suitable for mild-to-moderate stroke survivors [1, 35]. Additionally, only 34% of the participants had baseline AMPS motor scores below normative age expectation for healthy people, which for 73 years old is  $\pm 2$  SD from a mean of 2.15 (SD=0.53) [115]. This indicates that a minority of the patients in our sample had a potential for improvement.

The results for the process component of the AMPS testing had a slightly different pattern. The mean AMPS process score for those included in study 1 was 0.9 (SD=0.8), and 84% of our sample scored below 1.7. This is what is expected from 70% of all stroke survivors [118]. This indicates that study 1 included stroke survivors with slightly limited process skills compared to stroke survivors in other studies. The highest AMPS process score was 2.27 and the lowest score was -2.30. Compared to the highest (3.0) and lowest (-4.0) score possible on this scale, the patient population of study 1 had neither the most or least able in process skills. According to normative age expectations for healthy 73 years old people (i.e.,  $\pm 2$  SD from a mean of 1.62

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[SD=0.47]) [115], at baseline 36% of the participants in study 1 had a potential of improvement.

We found no significant effect of ESD on changed ADL ability (in terms of performance or independence) compared to traditional treatment. One explanation may be that the numbers of bed days in the stroke unit were about similar in all the treatment groups, having a median of 9, 8, and 8 days respectively, for the day-unit, home, and control groups. Thus, the effect of early discharge was equal in all groups. This is consistent with other research showing trends of shorter stays in hospital [24].

In a recently published protocol of a Swedish study, this trend of shorter hospital stays is currently being taken seriously [151]. The authors aimed to determine whether the current practice of very early discharge and follow-up rehabilitation at home was as useful for stroke survivors, as previous research on ESD suggested was for longer stays in hospital. The number of bed days may be further reduced in future stroke rehabilitation due to promising results of new methods of treatment. This is, for instance, the case for use of mechanical thrombectomy in acute ischemic stroke [152], indicating that the focus on even earlier discharge is reasonable for future studies.

Another explanation for why we did not find a significant effect of ESD on changed ADL ability is that high-quality treatment might have been applied very early on after stroke. Stroke survivors' ADL scores have increased during the last decades, which is probably a consequence of improved acute care treatment [24, 63]. Because study 1 was conducted in the context of a Norwegian RCT, we expect that clinical guidelines were adhered to in all follow-up interventions, meaning that high-quality treatment was given and likely resulted in better ADL recovery for all patients involved [153]. This may indicate that important aspects of treatment were relatively equal and that we should not expect significant differences in outcome between the groups. A previous Cochrane report also suggested that differences in ADL ability after follow-up in the municipality depend on whether patients receive appropriate rehabilitation

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[42]. This explanation is in line with the result of two RCTs using the AMPS as an outcome measure. They concluded that home and day settings for rehabilitation are equally effective [136, 137]. Although these studies were not conducted in the context of ESD, our results from study 1 are consistent with their conclusions.

Significant within-group changes in terms of AMPS performance was expected, since the greatest functional change occurs during the first 3 months of rehabilitation [60]. More surprising, however, was the lack of a significant change in terms of mRS performance, especially since another study from the ESD Stroke Bergen RCT that included all patients showed greater mRS benefits for the ESD groups [154]. Comparing baseline scores to the above-mentioned study, our study showed better ADL performance. This may reinforce our suspicion of limited sensitivity of the full mRS scale in detecting change in our sample and a possible ceiling effect in the dichotomised mRS scale. This ceiling may have been unwittingly introduced by favouring those most mildly affected by stroke.

Controlling for possible confounding factors, we found no associations between the AMPS outcomes and the ESD rehabilitation models. A significant association was found for the mRS (in terms of performance and independence). One explanation may be that the ESD models of rehabilitation in the main RCT (i.e., ESD Stroke Bergen) were targeted towards increased physical ADL performance sufficient to live independently in the community [3], which is the main focus of their primary outcome measure, the mRS [122]. Gain in the AMPS scores, would additionally demand treatment targeting the quality of performance, such as that directed towards reducing clumsiness and increasing efficiency when performing ADL tasks. This might have been more equally focused in the different treatment groups.

The association in study 1 found only for the mRS might reflect a possible strength of the ESD schemes regarding treatment directed at improving physical and social skills. For the mRS, our study revealed a strong association for both ESD groups compared to the control group (in terms of performance and independence). We are, however,

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limited in our conclusions. Since we lack information on the specific treatment given to the control group, we are left with only speculations as to the possible causes of this finding. It should be noted, however, that the strongest association were found for the ESD groups.

While assessing underlying impairment and socialising is part of the mRS [122, 123] and not the AMPS [115], the results of study 1 indicate that ESD is best suited towards improvement in social functioning and physical skills. The best rehabilitation model for stroke survivors with other needs justifies further investigation, however. Another explanation may be that mRS categories of assessing independence include the use of adaptive devices [122]; this would lead to a lower score on the AMSP [115]. We can, however, only speculate whether access to adaptive devices was easier for the participants in the ESD groups than for those who received traditional rehabilitation. One important contribution of our findings is identifying the need in future studies to clarify clearly the exact nature of the intervention received by the control group.

We also found the effect of kind of rehabilitation treatment (ESD and traditional) was weaker than the effect of age, indicating a decline in ADL ability with increased age. This outcome seems logical and is supported by previous research, even in healthy persons [67, 122, 155]. ADL ability at discharge was found to be relatively good in all AMPS measures of patients in study 1. High ADL scores at baseline, might be associated with favourable ADL ability in later stages of stroke rehabilitation [64]. Analysis of the association between the 3-month scores on the mRS and baseline AMPS process scores revealed increased mRS scores (lower ADL performance) and decreased AMPS process scores (lower process skills). Even if not significant, we found a similar result in the analysis using cut-off scores. Together these findings may indicate that mRS performance also reflects some process skills. This suggestion needs further investigation.



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Another sub-study of ESD Stroke Bergen reported a significant difference in self-reported ADL between the treatment groups [156]. Considering our results in light of these may confirm that a possible limitation exists in using pure, objective, standardised outcome measures when aiming to capture what is important to stroke survivors [84, 85]. Introducing the use of the AMPS or the mRS scales does not seem to enhance knowledge that healthcare professionals need to more fully understand individual patients' needs.

### **Specific findings of studies 2 and 3 - Interview studies**

In studies 2 and 3, the participants' stories revealed that entrance back into a meaningful life after stroke was hindered by changes in existential dimensions and emotional strain in their lives caused by a changed body. We found that coming to terms with the trauma of a changed body and self was a coping resource for patients. This involved getting familiar with 'new' bodily resources and limitations in daily activities and social settings, as well as comprehending the experienced discrepancies between body and will. These aspects were also highlighted more generally in previous research on stroke survivors' experiences [51, 157-159]. At the same time, we observed that cultivating hope of a life worth living was used strongly as a coping resource, which enabled the patients to continue their efforts at improving their condition. Hope as a crucial factor for coping with life disruptions more generally is underscored in previous literature [103, 111-114].

This situation of a changed health condition and recovery was the scene in which healthcare professionals entered and contributed and where the participants embraced most of the help they were offered. In our research, we found that successful recovery was built on exchange of mutual confidence between patient and healthcare professionals. Patients' and professionals' combined resources helped the patients proceed with their lives and cope with the challenges at hand. Mutual confidence between professionals and stroke patients is also underscored by Kirkevold as being

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crucial in the recovery processes [54]. Our findings of challenging encounters between patients and healthcare professionals and insufficient recovery, even in mild-to-moderate stroke survivors after 6-8 months, suggest, however, that the context of ESD and home rehabilitation was not fully developed to appropriately respond to the participants' needs.

One possible explanation for this lack of a developed treatment programme is found in previous research, which points to a changed body and self as particularly stressful and difficult to live with [51, 72, 76]. For the participants in our study, re-incorporating bodily based know-how was, at the best, experienced as a challenge. But, just as often, this process was perceived as a burden of uncertainty, one far beyond self-control. This indicates that healthcare professionals should pay more attention in helping to make the situation as comprehensible and manageable as possible and thereby establish helping patients acquire a sense of individual control [160]. The split they perceive between the body they knew and lived before stroke and the one they now experienced after stroke parallels the split they experienced between body and will when moving and acting. Task-specific treatment might re-establish fully or partially bodily 'know-how' about practical execution of valued tasks and activities [65, 102]. Cognitive understanding may be increased by explanations offered, support, and informed solutions [94, 105]. However, the emotional concerns following a changed body seems to take time and energy [159] and must be dealt with on their own terms.

The participants found it challenging to deal with the inconsistency in statements and actions among healthcare professionals. This became apparent especially in contacts with healthcare professionals not directly involved in the ESD service, like their GP and physiotherapists in the municipality. Since these professionals did not have access to information about the patients' overall situation, they might make statements to the patients that contradicted those made by professionals involved in the ESD service. These aspects are possible weak points in the rehabilitation scheme,

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especially when noting the crucial role given to the GP [95, 96] and our participants' and other stroke survivors' call for more physical training [52, 93]. Altogether, our study supports the need for cultivating close cooperation among all stakeholders involved with the patients [80, 96, 161], also within the context of ESD and home rehabilitation.

Another explanation for why the rehabilitation programme in the context of ESD may not have been fully developed to meet the participants' needs, may be that stroke survivors' processing of a changed body involves mobilisation of their social resources, a point made in other studies [36, 50, 74, 78-80, 97, 106, 149, 162]. For the participants' interviewed in our study, social affiliation was challenging because they were on sick leave, staying home alone, unable to leave the house, or being perceived differently by others, even by their close family members. As participation in social relationships may be considered to be more important than physical recovery after stroke [158], our participants' and other stroke survivors' desired venues to share their experiences with informed others [81]; this seems important for healthcare professionals to address. Even if home seems to be stroke survivors' preferred destination early after stroke [16] and healthcare professionals benefit from information and rehabilitation obtained through domestic surroundings [163], there might also be a risk of social isolation for stroke survivors [47, 76, 99]. An opportunity to socialise with other stroke survivors may have contributed in the sense of being a valuable yardstick to assess progress of their own development when struggling to create a meaningful life. Socialising would probably also have provided an opportunity to discuss stroke-related problems and vent out some frustration.

Previous research has also suggested that belonging in valued relationships is an important source of inspiration and is important for reality correction and confirmation of one's value to others [149]. We support the notion that healthcare professionals cannot be deemed as the only experts in the patients' life [111-113], which should bring the need for a more flexible service suited to meet stroke

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survivor's needs to the fore [80]. In order to strengthen mild-to-moderate stroke survivors understanding of a changed body and contribute to a successful adaption to a social life, implementing of ESD in the future might benefit from focusing more on the social belonging aspect of daily life, especially in the longer term after stroke. To the participants in our studies, this meant a more flexible service.

Successful processing of a changed body for stroke survivors may also involve finding a balance between bodily abilities and one's own wishes and needs [157], an area in which healthcare professionals are given a crucial negotiation role [54]. To the participants in our studies, bodily progress was closely intertwined with their hope of improvement. Antonovsky and other authors have promoted hope as an inner drive that gives patients something positive to cling to and direct their effort towards [103, 111-114]. This indicates that negotiation between realism and optimism emerges as a mined area. Even if hope was related to the present by representing a motivating factor in everyday life, hope is fundamentally intertwined in the past and future. The participants looked forward and hoped for a life worth living. This meant re-acquiring the ability to do at least some of what they had appreciated before the stroke and to belong again in valued fellowships. Hope as such was therefore related to the past, to the familiar and concrete [58, 72, 93]. The future was more uncertain, not least for those who did not know what to dare hope for. This suggests that challenging the patients' hope might take away some driving force in their life and reinforce uncertainty.

It is important for patients not to be overwhelmed by uncertainty and other emotional concerns. Other authors have stressed the need for healthcare professionals to promote sufficient emotional support [49-51, 54, 76, 77, 79]. This might involve addressing the reasonable and normal in survivors' emotional reactions to a highly demanding situation, encouraging the need to put feelings into words and thereby raise awareness of their existence. Doing this may help crystallise what it is all about and thereby help them to be able to discuss what steps to take next [54, 159]. We

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suggest that an additional focus on equality, engagement, and existential challenges might reduce the need for a psychologist, which was called for in our and previous research [106]. Hope and motivation might be the most important coping resources and might help keep helplessness and apathy at a distance [114]. Our findings of challenging encounters between healthcare professionals and participants, which seemed to contribute an extra burden to an already vulnerable situation for some, might be a reminder of how gingerly this process must proceed. In order to support mild-to-moderate stroke survivors' process of who to become after stroke, we suggest that healthcare professionals involved in ESD and home rehabilitation should further increase their attention to process-oriented communication, which was offered to some degree in the ESD Stroke Bergen [126]. This RCT promotes supportive communication and behavioural skills.

Additionally, processing the complexity of stroke is a gradual and prolonged process of transition and transformation [47]. Physical recovery mainly occurs within the first 3 months after stroke [8, 60-62], whereas the emotional burden of a changed body may be present for years afterward [50, 51, 72, 79, 106]. Our findings of struggling with bodily consequences, which can occur 6-8 months after even a mild-to-moderate stroke, indicates there is a need to extend the duration of home rehabilitation beyond the current 5-week time frame.

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## 6. Conclusions and implications

This thesis research has broadened our understanding of different aspects of daily life in patients with mild-to-moderate stroke following ESD and outpatient rehabilitation in the municipality. While the ‘doing’ aspects of daily life seem to be well addressed by this model of care –ESD and follow-up rehabilitation offered in the municipality– needs related to existential aspects of daily life seem to be left unmet. In this study, the core struggle of mild-to-moderate stroke survivors was coming to terms with themselves and life again 6-8 months after their stroke. This was so, despite the fact that the patients were assessed to be fully or almost independent in terms of ADL, a finding that only came out through in-depth analysis of interview material.

The ADL ability (performance or independence) of patients undergoing ESD intervention followed by rehabilitation at home or at a day unit was not superior to that of patients undergoing traditional rehabilitation offered in the community. Although, our study lacked the statistical power needed and thus, we could not provide clear recommendations on what type of intervention –ESD and home rehabilitation, ESD and day unit rehabilitation, traditional rehabilitation– would benefit mild-to-moderate stroke survivors the most. AMPS revealed that all treatments groups displayed increased ADL ability. This indicates that all three rehabilitation schemes improved the ADL ability of these patients. Some may argue, however, that this improvement might have happened regardless of treatment since sufficient time had elapsed (3 months) to allow this level of recovery to possibly occur. The results from our assessment using a secondary outcome measure (mRS) indicated that ESD models of rehabilitation might be preferable for patients with physical impairments and social restrictions.

We found that helping mild-to-moderate stroke survivors to again engage in valued activities and being part of valued relationships requires that healthcare professionals understand the existential challenges and emotional strain the stroke survivors

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experience. They also need to realise that these patients now have an altered view of their body and changed self. Existential aspects of daily life cannot easily be captured by traditional theoretical frameworks and standardised outcome measures, which are commonly used in stroke rehabilitation to assess patients. With current practices, then healthcare professionals might overlook essential needs that are existential in nature. Hence, we recommend that healthcare professionals involved in ESD and follow-up rehabilitation should pay extra attention to the existential and emotional burdens of stroke survivors, even those who suffer mild-to-moderate stroke. There is also a need to facilitate a discussion about which specific framework can emotional and existential needs be best understood. This study has pointed out possible weaknesses in the supportive part of ESD and offers suggestions for further improvement from a stroke survivors' perspective. Long-term follow-up when needed and flexibility in interventions also seem reasonable. After completion of the main study, ESD Stroke Bergen, the Municipality of Bergen changed their practice. Today, the patients' needs are met to a greater extent regarding their need of longer-term follow-up and flexibility of service.

In order to deal with the existential and emotional after-effects of mild-to-moderate stroke, engagement of personal coping resources appear to be essential. A crucial prerequisite of healthcare professionals' ability to facilitate successful management was mutual confidence expressed in encounters between patient and professionals. Mutual confidence is built through emotional support, engagement, and equality. Along these lines, healthcare professionals need to rely on and develop personal communication skills, as being able to communicate emotional support seems just as important as having professional expertise when it comes to building mutual confidence. Thus, future educational programmes for healthcare professionals should incorporate courses on how to further develop good communication skills as an essential component of their curriculum.

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## 7. Suggestions for further research

Many questions have emerged during the course of conducting research for this thesis, and I would like to highlight some. Due to the limited statistical power in study 1, we did not fully succeed in confidently answering our research question. Future studies that ensure having more patients at follow-up assessments may contribute to more clear recommendations. Using the AMPS as an outcome measure has proven to be challenging in stroke research, as seen in study 1. A clear lesson from that study is the need for a pilot study to identify, and hence avoid, some of the pitfalls revealed. Even if the sensitivity of the AMPS is shown to be superior over other commonly used outcome measures, its sensitivity for detecting change in stroke survivors will still have to be determined. Further methodological examination of the AMPS in even better designed studies may provide more answers on whether AMPS is a valid measure in stroke patients.

The existential and emotional strain observed in studies 2 and 3 seem to be very important in the eyes of the patients. However, these topics have received limited attention in current stroke research and stroke rehabilitation. To broaden the evidence in which healthcare professionals base their decisions, researchers need to focus on stroke survivors' experiences in future research. For example, determining who benefits from different interventions would enable healthcare professionals to better tailor rehabilitation services to the individual needs of patients. In these studies we found that the personal skills of healthcare professionals played an important role in the recovery of stroke survivors. Future research, therefore, should also focus efforts on determining what makes a successful stroke therapist, according to the perspectives of both healthcare professionals and patients.



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